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Austria

Number of Staff Involved in Medical Genetic Service Provision

No information is available.

Departments, Centres and Institutions Involved in Genetic Services

Major centres offering a broad range of genetic services

Institut für Medizinische Biologie und Humangenetik, Universität Innsbruck – Humangenetische Untersuchungs- und Beratungsstelle

Pre- and postnatal cytogenetics, molecular cytogenetics, Molecular genetics, tumour cytogenetics, DNA analysis, biochemical genetics, dysmorphology/genetic syndromology, genetic counselling

Institut für Medizinische Biologie und Humangenetik, Universität Graz – Humangenetische Beratungsstelle

Pre- and postnatal cytogenetics, molecular cytogenetics, tumour cytogenetics, DNA analysis, biochemical genetics, dysmorphology/genetic syndromology, genetic counselling.

Centres offering restricted genetic services

Kinderklinik (Landeskrankenhaus Salzburg), Abteilung Klinische Genetik
Postnatal cytogenetics, molecular cytogenetics, dysmorphology/genetic syndromology, genetic counselling

St Anna Kinderspital Wien, Forschungsinstitut für krebskranke Kinder
Postnatal cytogenetics, molecular cytogenetics, tumour cytogenetics, DNA analysis

Wilhelminen-Spital Wien, Genetische Beratungsstelle
Pre- and postnatal cytogenetics, genetic counselling

Institut für Allgemeine Biologie, Universität Wien
Postnatal cytogenetics, molecular cytogenetics, tumour cytogenetics

Centres offering genetic services in special areas/diagnosis/indications

Universitätsklinik für Pädiatrie, Universität Wien, Labor für Angeborene Stoffwechselstörungen
Biochemical genetics, newborn screening, DNA diagnosis of inborn errors of metabolism

Universitätsklinik für Psychiatrie, Allgemeines Krankenhaus Wien
Huntington disease

Österreichisches Zentrum für Screening, Zentrallabor, SMZO-Donauspital, Wien
DNA diagnosis

Klin. Abteilung für Neuropathologie und Neurochemie, Allgemeines Krankenhaus Wien
Metachromatic leucodystrophy, adrenoleucodystrophy

Institut für Anatomie, Universität Wien
Duchenne muscular dystrophy, Becker muscular dystrophy

Zentrallaboratorium und Blutbank, Krankenanstalt Rudolfstiftung Wien
Haemoglobinopathies, DNA diagnosis

Innere Medizin IV, Abtl. f. Gastroenterologie und Hepatologie, Allgemeines Krankenhaus Wien

Morbus Wilson, haemochromatosis

Klinisches Institut für Medizinische und Chemische Labordiagnostik, Allgemeines Krankenhaus Wien

DNA diagnosis, coagulation defects

Arbeitsgruppe f. Stoffwechselerkrankungen, Univ. Kinderklinik Graz
Inborn errors of metabolism

Klinisches Institut für Medizinische Chemische Labordiagnostik, Allgemeines Krankenhaus Wien

DNA diagnosis, complement defects

Stoffwechsellabor, Univ. Kinderklinik Wien
Inborn errors of metabolism

Innere Medizin I, Abteilung für Hämatologie und Hämostaseologie, Allgemeines Krankenhaus Wien

DNA diagnosis, coagulation defects

Workloads

No information is available.

Patient organisations

No information is available.

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Belgium

Departments, Centres, Institutions Involved in Genetic Services

CHU de Liège
Laboratoire de Biochimie Génétique
Pathologie B23
CHY Sart Tilman
B-4020 Liege
Tel. +32 41 30 71 23, Fax +32 41 56 29 74/66 81 46

Medische Genetica
Vrije Universiteit Brussel
Fakulteit Geneeskunde en Farmacie
Laarbeeklaan 103/E
B-1090 Brussels
Tel. +32 2 477 45 89, Fax +32 2 477 58 00

Universitaire Instelling Antwerpen
Medische Genetica
Universiteitsplein 1
B-2610 Wilrijk
Tel. +32 3 820 25 70, Fax +32 3 820 22 48

Centre de Génétique de l'UCL
Avenue Em Mounier 52, Tour Vesale 5220
B-1200 Bruxelles
Tel. +32 2 764 53 50/764 52 20, Fax +32 2 764 52 22

Centre de Génétique Médicale
Institut de Morphologie Pathologique
Allée des Templiers 41
B-6280 Loveral (Gerpennes)
Tel. +32 71 43 79 01/47 30 47, Fax +32 71 47 15 20

Facultair Centrum voor Medische Genetica
Academisch Ziekenhuis RUG
Blok A - 1ste verd, De Pintelaan 185
B-9000 Gent
Tel. +32 9 240 36 03, Fax +32 9 240 49 70

Centre de Génétique
Batiment Transfusion (02)
Campus Erasme, 808 Lenniske baan
B-1070 Bruxelles
Tel. +32 2 555 64 30, Fax +32 2 555 64 40

Centrum voor Menselijke Erfelijkheid
K U Leuven, Campus Gasthuisberg
Herestraat 49
B-3000 Leuven
Tel. +32 16 34 58 60/34 59 03, Fax +32 16 34 59 97

Workloads

Centre for Human Genetics UCL

Cliniques Universitaires Saint-Luc, Brussels. Genetic counselling for prenatal and paediatric disorders, classical constitutional cytogenetics, molecular analyses of the most frequent diseases. Childhood leukaemias (with the Department of Paediatrics) - active member of the 'Groupe Français de Cytogénétique Hématologique' (GFCH). Special interest in paediatric and adult neuromuscular disorders. Follow-up of prenatal diagnosis >85% of pregnancies. Huntington disease (with psychiatric department) - French-speaking association founded. Prevention and genetic screening of familial medullary thyroid carcinoma (MEN2A), breast cancer and polyposis coli. Closely linked to the Academic Hospital in Brussels - masters and PhD study.

The Human Genetics Centre of the Free University of Brussels

Metabolic clinic, department of molecular oncology. Special interest of centre is identifying mutations in thyroid diseases. The primary aim of the centre is prevention, the secondary aim, early diagnosis. Neonatal screening for amino acid disorders (PKU, maple syrup urine disease, histidine, tyrosine and methionine disorders), hypothyroidism and galactosaemia. At-risk population screening for specific disorders (cystic fibrosis, fragile X, haemoglobinopathies, Tay-Sachs) before pregnancy or early pregnancy. Family studies follow carriers, all at risk have received genetic tests. Triple test for Down syndrome is more commonly performed by gynaecologists. Pilot population screening programmes for some specific disorders. The centre is responsible at the national level to the Superior Council for Genetics.

Institute de Pathologie et de Génétique

Only centre in Belgium NOT attached to a university. Large clinical genetics department. It covers a large area of French-speaking western Wallonia i.e. 5,200 km² with 1,100,000 inhabitants and 15,000 births per annum. Services are offered to 23 official hospitals through monthly or occasional clinical genetics consultations. Specialises in congenital malformations from pathological and epidemiological perspectives. Clinical evaluation and genetic counselling for mental retardation. Follow-up studies 3 years after initial genetic counselling via questionnaire to assess impact and middle-term effects. This is done by social workers and psychologists. 80,000 biopsy samples analysed annually - special service for cancer-prone families and a concerted molecular cytogenetic analysis of bone marrow and solid tumour specimens.

Human Genetics Centre of Liège

Genetic and biochemical services. Neonatal screening of metabolic diseases; approx. 17,000 newborns surveyed per annum. Same number screened for hypothyroidism and 21-hydroxylase deficiency. Screening programme for creatine phosphokinase and α_1 -antitrypsin covers approx 17,000 births. Quality control by the British Biochemical Society Programme. Triple test for Down syndrome using a maternal serum marker uses a specific technique with dried blood for 15,000 tests per year. Pilot programmes for screening pregnant women for cystic fibrosis and fragile X. Pregnant women tested annually in the general population are approximately 23,000/37,000 (estimation). After 4 years, the number of trisomic 21 births has been reduced by 66% in the region of Wallonia.

Human Genetics Centre of Leuven

Nine video programmes about genetic syndromes. One video programme with an introductory survey on genetics has been produced especially for education of the general public. Most institutes for mentally retarded patients in Belgium are visited regularly by physicians from the centre in Leuven and new patients are then selected for chromosomal or molecular investigations of the cause of mental retardation.

Patient Organisations

No information is available.

Bulgaria

Departments, Centres and Institutions Involved in Genetic Services

No information is available.

Workloads

No information is available.

Patient Organisations

No information is available.

Croatia

Departments, Centres and Institutions Involved in Genetic Services

Division of Genetics, Inherited Metabolic Disorders
Department of Paediatrics
University Hospital 'Rebro'
Tel. +385 1 213087, Fax +385 1 210900

Division of Genetics
Department of Paediatrics
Children's University Hospital
Zagreb
Tel. +385 1 440455, Fax +385 1 4551308

Laboratory for Molecular Genetics
 Department of Clinical Laboratory Diagnostics
 University Hospital Centre
 Zagreb
 Tel. +385 1 212079, Fax +385 1 212079

Division of Neurology and Genetics
 Department of Paediatrics
 University Hospital Centre
 Split
 Tel. +385 21 515055, Fax +385 21 365738

Department of Molecular Medicine
 Institute 'Rudjer Boskovic'
 Zagreb
 Tel. +385 1 4561111, Fax +385 1 424239

Institute for Biology
 Medical School University of Rijeka
 Rijeka
 Tel. +385 51 651111, Fax +385 51 62646

Department of Gynaecology
 General Hospital Sv. Duh
 Zagreb
 Tel. +385 1 171111, Fax +385 1 579248

Institute for Clinical and Experimental Laboratory Oncology
 University Hospital 'Sestre milosrdnice'
 Zagreb
 Tel. +385 1 178666, Fax +385 1 172453

Department of Gynaecology
 University Hospital 'Merkur'
 Zagreb
 Tel. +385 1 219988, Fax +385 1 212415

Workloads

Number of genetic counselling and cytogenetic analyses per year in Croatia

PUZ	PCUZ	PUS	OSMZ	GMZ	BPR	GSDZ	NZ	Total
<i>Counsellings/year</i>								
720	1,640	300	-	260	40 100	480	recently set up	3,540
<i>Cytogenetic analyses (prenatal in parentheses)</i>								
2,385 ^a (920)	456 ^a (-)	400 ^a (-)	240 ^a (-)	260 (200 ^b)	400 (100)	1,200 (840)	-	5,341 (2,060)

^a Cancer cytogenetics.

^b Placental biopsies.

For the first two and the fifth centre, the numbers are given for 1995, while for others annual averages are given. PUZ = Department of Paediatrics, University Hospital Centre, Zagreb; PCUZ = Department of Paediatrics, Children's University Hospital Zagreb; PUS = Department of Paediatrics, University Hospital Centre, Split; OSMZ = Institute of Oncology, University Hospital 'Sestre milosrdnice', Zagreb; GMZ = Department of Gynaecology, University Hospital 'Merkur', Zagreb; BPR = Institute of Biology and Department of Paediatrics, University Hospital Centre, Rijeka; GSDZ = Department of Gynaecology, General Hospital 'Sv. Duh', Zagreb; NZ = Department of Neurology, University Hospital Centre, Zagreb.

Patient Organisations

There are some consumer organisations (mainly for specific diseases including PKU, cystic fibrosis, mucopolysaccharidoses and Duchenne muscular dystrophy) and some have international links (galactosaemia, spinal muscular atrophy and mucopolysaccharidoses).

Cyprus

Departments, Centres and Institutions Involved in Genetic Services

The Cyprus Institute of Neurology and Genetics
 PO Box 3462
 C-1683 Nicosia

Thalassaemia Centre
 Archbishop Makarios Hospital
 Acropolis
 Nicosia

Centre for the Prevention of Mental Retardation
 PO Box 6617
 C-3309 Limassol

Workloads

No information is available.

Patient Organisations

No information is available.

Czech Republic

Departments, Centres and Institutions Involved in Genetic Services

Department of Clinical Genetics^{A, B, C}
 Ústí nad Labem
 Tel. +42 47 46751, Fax +42 47 42752

Department of Clinical Genetics^{A, B}
 Ěeské Budjovice
 Tel. +42 38 7873007

Department of Clinical Genetics^{A, B, C}
 Brno
 Tel. +42 5 45122489

Institute of Medical Genetics and Fetal Medicine^{A, B, C}
 Olomouc
 Tel. +42 68 5414906

Motol University Hospital, 2nd Medical Faculty^{A, B, C, D}
 Prague
 Tel. +42 2 24431111

1st Internal Clinic, 1st Medical Faculty^D
 Prague
 Tel. +42 2 24963114

Department of Clinical Genetics^{A, B, C}
 Plzeň
 Tel. +42 19 277077

Department of Clinical Genetics^{A, B, C}
 Hradec Králové
 Tel. +42 49 23331, Fax +42 49 495832012

Department of Clinical Genetics^{A, B, C}
 Prague
 Tel. +42 2 24904111

Department of Clinical Genetics^{A, B, C}
 Prague
 Tel. +42 2 4728227, Fax +42 2 4728227

Institute of Biology^C
 1st Medical Faculty
 Prague
 Tel. +42 2 299492

3rd Internal Clinic^{C, D}
 1st Medical Faculty
 Prague
 Tel. +42 2 24962827

Department of Clinical Genetics^{A, B}
 Prague
 Tel. +42 2 24802111

Institute of Haematology^{C, D}
 Prague
 Tel. +42 2 295265

Institute of Health of Child^C
 Brno
 Tel. +42 5 7262854

Institute of Haematology Medical Faculty^{C, D}
 Olomouc
 Tel. +42 68 414102

Institute of Metabolic Diseases^{A, C}
 Prague
 Tel. +42 2 295202

Department of Clinical Genetics^{A, B}
 Ostrava-Poruba
 Tel. +42 69 6982212

Department of Clinical Genetics^A
 Litomyšl
 Tel. +42 464 618521

Private Genetic Department^{A, B}
 Plzeň
 Tel. +42 19 7241529

Private Genetic Department^A
 Ostrava
 Tel. +42 69 233021 Fax +42 69 233021

Private Genetic Department^{A, B}
 Hradec Králové
 Tel. +42 49 618670

Private Genetic Department^A
 Ostrava
 Tel. +42 69 261754

Private Genetic Department^A
 Sokolov

Workloads

No information is available.

Patient Organisations

No information is available.

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Denmark

Departments, Centres and Institutions Involved in Genetic Services

Department of Medical Genetics,
 Panum Institute, University of Copenhagen
 Blegdamsvej 3
 DK-2200 København Ø
 Tel. +45 35327816, Fax +45 31393373

John F. Kennedy Institute
 Gl Landevej 7
 DK-2600 Glostrup
 Tel. +45 4326 0100, Fax +45 4343 1130

Department of Clinical Biochemistry and Genetics
 Odense University Hospital
 DK-5000 Odense C
 Tel. +45 6611 1725, Fax +45 6541 1911

Department of Clinical Genetics
 County Hospital of Vejle
 DK-7100 Vejle
 Tel. +45 7572 7233, Fax +45 7584 1336

Clinical Genetics Department
 Aarhus University Hospital
 Bartholin Bygningen
 Universitetsparken
 DK-8000 Aarhus C
 Tel. +45 89494362, Fax +45 89494370

Department of Clinical Genetics
 Juliane Marie Centre
 Rigshospitalet, Blegdamsvej
 DK-2100 København Ø
 Tel. +45 3545 4062, Fax +45 3545 4072

A = Genetic counselling; B = cytogenetic laboratory; C = molecular laboratory; D = oncocytogenetic laboratory.

Workloads

Diagnostic samples analysed in 1994

	Dept. Medical Genetics University of Copenhagen	Dept. Clinical Genetics Rigshospitalet Copenhagen	John F. Kennedy Institute Glostrup	Dept. Clinical Genetics Vejele	Dept. Clinical Genetics Arhus	Section Clinical Genetics Odense	Total
Cytogenetics							
Blood (including FISH)	112	782	1,132	327	667		3,020
Amnio/CVS		2,587/2,073	412/567	724/24	1,551/716		5,274/3,380
Molecular genetic analyses	92						
Prenatal		74	30		25	30	129
Postnatal		1,056	630 ^a		130		1,938
Biochemical (inborn errors)	2						
Prenatal		10	32 ^a				42
Postnatal		2,604 ^b	3,526 ^c				6,130
Number of genetic counsellings (patient consultations)	300		250	400	200 ^e	160	1,810
Low risk ^d		3,119					
High risk		500					

^a Includes investigations on samples from abroad.

^b 1,102 blood, 1,502 urine.

^c 3,272 blood, 254 urine.

^d Pregnant low-risk e.g. maternal age.

^e In addition, 200 consultations were held at local departments.

Patient Organisations

No information is available.

Finland

Departments, Centres and Institutions Involved in Genetic Services

Department of Medical Genetics
University of Helsinki
PO Box 21 (Haartmaninkatu 3)
FIN-00014 Helsinki
Tel. +358 9 43461, Fax +358 9 434 6677

Department of Medical Genetics
University of Turku
Kiinamylynkatu 10
FIN-02520 Turku
Tel. +358 2 33371, Fax +358 2 3337300

Department of Human Molecular Genetics
National Public Health Institute
Mannerheimintie 166
FIN-00300 Helsinki
Tel. +358 9 47441, Fax +358 9 474408

National Research and Development for Welfare and Health
National Public Health Institute
PO Box 220
FIN-00531 Helsinki
Tel. +358 9 3967 2376, Fax +358 9 3967 2324

Helsinki University Central Hospital
Department of Clinical Genetics
Haartmaninkatu 2
FIN-00290 Helsinki
Tel. +358 0 4711, Fax +358 0 471 6089

Helsinki University Central Hospital
Department of Obstetrics and Gynaecology
Prenatal Genetics
Haartmaninkatu 2
FIN-00290 Helsinki
Tel. +358 9 4711, Fax +358 9 471 4906

Helsinki University Central Hospital
Laboratory of Molecular Genetics
Haartmaninkatu 4
FIN-00290 Helsinki
Tel. +358 0 4711, Fax +358 0 471 4001

Department of Clinical Genetics
Oulu University Hospital
Kajaanintie 52
FIN-90220 Oulu
Tel. +358 8 315 2011, Fax +358 8 315 4499

Department of Clinical Genetics
Tampere University Hospital
PO Box 2000
FIN-33521 Tampere
Tel. +358 3 2475305, Fax +358 3 2474361

Department of Clinical Genetics
Kuopio University Hospital
PL 2000
FIN-70200 Kuopio
Tel. +358 17 172147, Fax +358 17 172726

Vaestoliitto, The Family Federation of Finland
Department of Medical Genetics
Kalevankatu 16
FIN-00100 Helsinki
Tel. +358 9 616 22246, Fax +358 9 645 018

The Finnish Red Cross
Blood Transfusion Service
Kivihaantie 7
FIN-00310 Helsinki
Tel. +358 0 580 1256, Fax +358 0 580 1397

Folkhälsan Department of Medical Genetics
Topeliusgatan 20
FIN-00250 Helsingfors
Tel. +358 9 43 491, Fax +358 9 4349 352

Private laboratories

Medix Ltd
Nihtisillankuja 1
FIN-02630 Espoo
Tel. 358 0 525 6222, Fax 358 0 525 6211

United Laboratories Ltd.
Hoylaamotie 14
FIN-00380 Helsinki
Tel. +358 0 50603470, Fax +358 0 50605410

The Rinnekoti Institution for the Mentally Retarded
FIN-02980 Espoo
Tel. +358 0 8551289, Fax +358 0 8551274

Workloads

See table 2 in Dimension 1 (main text)

Patient Organisations

See main text.

France

Departments, Centres and Institutions Involved in Genetic Services

Information is available on Internet
(<http://www.infobiogen.fr/services/orphanet>).

Workloads

No information is available

Patient Organisations

A list is available on Internet (<http://www.infobiogen.fr/services/orphanet>).

Guidelines and Laws

Génétique et Médecine: de la prédiction à la prévention. Les cahiers du Comité Consultatifs National d'Ethique pour les sciences de la vie et de la santé, No. 6, 1996.

Lois No. 94-653 and No. 94-654, July 29, 1994.

Décrets No. 95-558 and 95-5569, May 6, 1995.

Germany

Number of Staff Involved in Medical Genetic Service Provision

As of December 1996, 441 geneticists were members of the Board of Medical Genetics.

Departments, Centres and Institutions Involved in Genetic Services

Genetic counselling services [Med Genet 1995;3:389-391]

Private solo practice in genetic counselling	
Obstetrician	13
Paediatrician	11
GP	1
Specialist (human genetics)	14
Others	7

Private group practices	
Centres in university human genetics departments	35
Centres at community/friendly society hospital	15
Centres at public health facility	2

Cytogenetic Laboratories [P. Miny, Institut für Humangenetik, Münster, 1995]

University based	25
Community/friendly society hospital	4
Privately owned	26
Total	55

Molecular genetic laboratories [Med Genetik 1995;7S:45-46]

University based	61
Community/friendly society hospital	2
Privately owned	10
Total	73

Workloads

[Source: Nippert I, Nippert RP, Horst J, Schmidtke J: Die medizinische-genetische Versorgung in Deutschland. Med Genetik 1997;2:188-205]. In 1995: number of amniocenteses/ CVS in former FRG states and East Berlin paid by sickness funds = 61,794; chromosomal diagnostics from blood samples paid by sickness funds in former FRG states and East Berlin = 27,601, and genetic counselling paid by sickness funds in former FRG states and East Berlin = 32,777.

Persons diagnosed by DNA probes in 1994: 13,436 [Berufsverband Medizinische Genetik, 1995].

Patient Organisations

More than 80 exist.

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Greece

Number of Staff Involved in Medical Genetic Service Provision

No information is available.

Departments, Centres and Institutions Involved in Genetic Services

- Aghia Sofia Children's Hospital
GR-11527 Athens
Tel. +301 7771811
Cytogenetics, genetic counselling, molecular genetics, prenatal diagnosis
- Alexandra Hospital
80 Vas. Sofias Ave
GR-11528 Athens
Tel. +301 8951478
Clinical genetics, genetic counselling
- Alfalab (private)
8 Anastasiou St
GR-11524 Psychiko
Tel. +301 6929420
Molecular genetics, cytogenetics
- Asklepieion Hospital
1 Vas Pavlou St
GR-16673 Voula
Tel. +301 8951478
Clinical genetics, genetic counselling
- Eginition Hospital
72 Vas. Sofias Ave
GR-11528 Athens
Tel. +301 7244917
Neurological genetics
- Evangelismos Hospital
47 Ypsilantou St
GR-11521 Athens
Tel. +301 7220001, x2289
Cytogenetics, genetic counselling, oncogenetics
- Genetic Diagnostic Center (private)
86 Vas. Sofias Ave
GR-11528 Athens
Tel. +301 7705010
Genetic counselling, metabolic diseases, clinical genetics, cytogenetics
- Institute of Child Health
GR-11527 Athens
Tel. +301 7709241, 7753030
- Laikon Hospital
(1st Department of Medicine, University of Athens)
GR-11527 Athens
Molecular genetics, haemoglobinopathies
- School of Dentistry, University of Athens
Genetics and Stomatology Clinic
GR-11527 Athens
Tel. +301 7701341
Orofacial genetics
- P. & A. Kyriakou Children's Hospital
(a) Department of Paediatrics, Faculty of Nursing
GR-11527 Athens
Tel. +301 7709316
Clinical genetics, genetic counselling

- P. & A. Kyriakou Children's Hospital
(b) Second Department of Paediatrics
University of Athens
Tel. +30 1 7791935
Clinical genetics, cytogenetics, counselling

- University Hospital of Ioannina
GR-450001 Ioannina
Tel. +30 651 33653
Cytogenetics

- University of Patra
GR-26443 Rio
Tel. +30 61 997621
Cytogenetics

- AHEPA Hospital
GR-54100 Thessaloniki
Tel. +30 1 933513
Cytogenetics, clinical genetics, genetic counselling

- Hippokrateion Hospital
GR-54100 Thessaloniki
Tel. +30 1 837921
Clinical genetics, cytogenetics, genetic counselling

Workloads

No information is available.

Patient Organisations

No information is available.

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Hungary

Departments, Centres, Institutions Involved in Genetic Services

See below.

Workloads

Genetic counselling clinics in Hungary

	Number of staff		Days/ week	Total hours/ week	Cyto- genetic laboratory	New couples/all visits				
	MD	others				1990	1991	1992	1993	1994
Budapest: Haynal Imre Medical University, Department of Obstetrics and Gynaecology, H-1135 Szabolcs u. 35, Tel./Fax +36 1 270 22 12	2	1	2	6	yes	/622	/1,375	/1,049	/943	/1,157
Budapest: Department of Human Genetics and Teratology, NIH, WHO Collaborating Centre, H-1148 Bolgárkerék u. 3, Tel./Fax +36 1 163 52 72/163 22 29	3	2	5	20	yes	2,402/4,180	2,380/4,174	2,804/5,265	2,241/4,284	2,345/5,003
Budapest: Schöpf-Merei Ágost Hospital and Maternity Care Centre, H-1092 Knézich u. 14, Tel. +36 1 215 10 55	1	3	2	6	yes	54/136	446/1,114	922/2,305	1,012/2,530	912/2,279
Budapest: Schöpf-Merei Ágost Hospital and Maternity Care Centre, H-1092 Knézich u. 14, Tel. +36 1 215 10 55, 1 217 16 33/157	1	1	2	4	yes	150/321	152/337	133/288	182/401	179/411
Budapest: Semmelweis University of Medicine, Department of Paediatrics II, H-1094 Tüzoltó u. 7-9, Tel. +36 1 215 13 80, Fax +36 1 217 57 70 E-Mail fekyö@gyer2.sote.hu	3	0	3	14	yes	/444	/493	/384	/419	/366
Budapest: I. Department of Obstetrics and Gynaecology, Semmelweis University Medical School, H-1088 Baross u. 27, Tel. +36 1 210 03 15, Fax +36 1 114 02 31	2	2	3	27	yes	219/402	1,321/3,240	1,872/4,760	2,020/4,705	2,310/6,221
Debrecen: University Medical School, Department of Obstetrics and Gynaecology, H-4012 Nagyerdei krt. 98, Tel. +36 52 417 144, Fax +36 52 417 577	2	1	4	20	yes	1,784/3,529	1,293/4,199	1,460/4,333	1,666/4,652	1,439/4,440
Eger: Markhot Ferenc County Hospital, Genetic Counselling, H-3301 Pf. 15, Fax +36 36 410 816	3	2	1	4	yes	80/80	373/549	403/849	262/594	326/694
Győr: Petz Aladár County Hospital Clinical-Genetics Centre, H-9002 Magyar u. 8, Tel. +36 96 418 244	4	0	2	5	yes	396/617	394/461	580/829	458/510	480/518
Miskolc: County Hospital of Borsod-Abaúj-Zemplén County, Department of Obstetrics and Gynaecology, H-3501 Szentpéteri kapu 72-76, Tel. +36 46 321 211, Fax +36 46 323 694	1	1	1	6	yes	-	-	770/1,052	686/883	718/980
Pécs: University of Medicine, Department of Paediatrics, Division of Genetics, H-7623 József A. u. 4, Tel. +36 72 310 144, Fax +36 72 314 937	3	2	3	6	yes	195	174	204	180	253
Pécs: University Medical School, Department of Obstetrics and Gynaecology, H-7624 Édesanyák u. 17, Tel. +36 72 324 122	1	0	2	2	yes	170/235	192/246	240/276	260/315	310/350
Szeged: Szent-Györgyi University of Medicine, Institute of Medical Genetics, H-6720 Híd u. 6, Tel. +36 62 312 629	1	2	3	9	yes	1,695	1,711	1,652	1,729	1,645
Szolnok: County Centre for Genetic Counselling, H-5004 Tószegi u. 21, Tel. +36 56 421 521/259	2	1	2	4	no	-	85/90	125/137	109/115	125/130
Szombathely: Markusovszky Hospital, Department of Paediatrics, H-9007 Markusovszky u. 3, Tel. +36 94 311 542, Fax +36 94 327 873	1	1	1	3	yes	290	329	329	319	265
Zalaegerszeg: County Hospital, H-8901 P.O. Box 24, Tel. +36 94 311 410 (ext. 1580)	1	4	2	5	yes	345	294	264	267	375

Cytogenetic laboratories in Hungary

	Number of staff		Specific profile	Number of chromosomal exams/pathological karyotypes				
	gradu- ated	assis- tants		1990	1991	1992	1993	1994
Budapest, Haynal Imre Medical University, Department of Obstetrics and Gynaecology, H-1135 Szabolcs u. 35, Tel./Fax +36 361 270 22 12	2	4	PLC	122/17	98/16	103/6	55/8	125/15
Budapest. Department of Human Genetics and Teratology, NIH, WHO Collaborating Centre, H-1148 Bolgárkerék u. 3, Tel./Fax +36 1 163 52 72/1 163 22 29	1	3	PLC	219/24	296/28	332/29	290/17	288/17
Budapest: National Institute of Haematology, Blood Transfusion and Immunology, H-1113 Daróci u. 24, Tel. +36 166 58 22, Fax +36 166 60 04	2	3	PLC bone marrow (haematological malignancies)	502/103	514/119	499/142	387/107	607/180

Cytogenetic laboratories in Hungary (continued)

	Number of staff		Specific profile	Number of chromosomal exams/pathological karyotypes				
	gradu- ated	assis- tants		1990	1991	1992	1993	1994
Budapest: Schöpf-Merei Ágost Hospital and Maternity Care Center, H-1092 Knézich u. 14, Tel. +36 1 215 10 55	2	5	PLC	-	150/8	142/9	132/6	115/8
Budapest: Semmelweis University of Medicine, Department of Paediatrics II, H-1094 Tüzoltó u. 7-9, Tel. +36 1 215 13 80, Fax +36 1 217 57 70, E-Mail fekgyo@gyer2.sote.hu	3	2	PLC bone marrow	337/71 77/20	396/110 56/15	302/57 86/9	310/77 94/13	274/56 112/25
Budapest: Semmelweis University of Medicine, Department of Forensic Medicine, H-1091 Üllői út 93, Tel. +36 1 215 73 00	1	3	PLC (paternity)	10/3 (198)	7/4 (156)	14/7 (211)	9/3 (162)	14/5 (193)
Budapest: I. Department of Obstetrics and Gynaecology, Semmelweis University Medical School, H-1088 Baross u. 27, Tel. +36 1 210 03 15, Fax +361 114 02 31	3	2	PLC	26/4	121/102	163/37	142/86	176/92
Debrecen: University of Medicine, Department of Paediatrics, H-4032 Péchy u. 28, Tel. +36 52 411 600	1	3	PLC bone marrow	131/31 155/28	137/33 173/29	134/26 136/27	138/28 224/42	129/25 186/61
Debrecen: University Medical School, Department of Obstetrics and Gynaecology I, H-4012 Pf. 37, Tel. +36 52 417 144/4044, Fax +36 52 414 577	2	2	PLC	27/2	72/4	57/6	46/4	40/5
Eger: Markhot Ferenc County Hospital, Genetic Laboratory, H-3301 Pf. 15	2	1	PLC (including bone marrow)	156/11	200/27	218/20	126/13	186/21
Győr: Petz Aladár County Hospital Clinical-Genetics Centre, H-9002 Magyar u. 8, Tel. +36 96 418 244	1	4	PLC bone marrow	120/29 6/6	119/22 14/8	115/24 16/3	90/14 17/7	126/20 13/6
Miskolc: County Hospital of Borsod-Abaúj-Zemplén County, Department of Obstetrics and Gynaecology, H-3501 Szentpéteri kapu 72-76, Tel. +36 46 321 211, Fax +36 46 323 694	1	1	PLC	-	-	25/8	91/14	133/19
Pécs: University Medical School, Department of Paediatrics, Division of Genetics, H-7623 József A. u. 4, Tel. +36 72 310 144, Fax +36 72 314 937	3	2	PLC and bone marrow	154/40	147/23	163/24	152/20	158/31
Szeged: Szent Györgyi University of Medicine, Institute of Medical Genetics, H-6720 Somogyi B. út 4, Tel. +36 62 455 133, Fax +36 62 312 529	4	5	PLC	242/63	264/28	277/38	266/28	274/39
Szombathely: Markusovszky Hospital, H-9701 Deák F. u. 2, Tel. +36 94 311 490	0	3	PLC bone marrow	47/7 21/15	55/14 20/12	61/10 16/9	56/25 33/14	55/12 35/25
Zalaegerszeg: County Hospital, H-8901 P.O. Box 24, Tel. +36 94 311 410 (ext. 1580)	1	4	PLC	106/21	107/10	112/15	73/9	110/9

PLC = Peripheral lymphocyte culture.

Fetal diagnostic centres (and number of cytogenetic exams) in Hungary

	Number of staff		Number of cytogenetic exams/pathological karyotypes									
	MD	others	1990		1991		1992		1993		1994	
			CVS	AC	CVS	AC	CVS	AC	CVS	AC	CVS	AC
Budapest: Haynal Imre Medical University, Department of Obstetrics and Gynaecology, Prenatal Diagnostic Centre, H-1135 Szabolcs u. 35, Tel./Fax +36 1 270 22 12	2	4	393/19	32/4	357/13	44/3	307/12	14/2	301/20	32/3	258/8	30/4
Budapest: Schöpf-Merei Ágost Hospital and Mother Protecting Centre I, H-1092 Knézich u. 14, Tel. +36 1 215 10 55	2	5	17/1		205/19		408/22		502/28	16/5	525/21	39/5
Budapest: I. Department of Obstetrics and Gynaecology, Semmelweis University Medical School, H-1088 Baross u. 27, Tel. +36 1 210 03 15	3	2	15/1	38/1	47/2	572/9	38/4	726/11	57/3	972/17	64/5	1,121/22
Debrecen: University Medical School, Department of Obstetrics and Gynaecology, H-4032 Nagyerdei krt. 98, Tel. +36 52 417 144, Fax +36 52 417 577	1	2	-		72/3	32/2	55/1	233/17	38/6	317/8	35/6	335/15

Fetal diagnostic centres (and number of cytogenetic exams) in Hungary (continued)

	Number of staff		Number of cytogenetic exams/pathological karyotypes									
	MD	others	1990		1991		1992		1993		1994	
			CVS	AC	CVS	AC	CVS	AC	CVS	AC	CVS	AC
Győr, Petz Aladár County Hospital, Clinical Genetics Centre, H-9002 Magyar u. 8, Tel. +36 96 418 244	5	2	76/5		103/4		128/7		141/10		139/5	
Pécs: University Medical School, Obstetrics and Gynaecology, H-7624 Édesanyák u. 17, Tel. +36 72 324 122; Department of Paediatrics, Division of Genetics, H-7623 József A. u. 4, Tel. +36 72 310 144, Fax +36 72 314 937	0	1	76		92		102		100		114	
Szeged: Szent Györgyi University of Medicine, Institute of Medical Genetics, H-6720 Somogyi B. út 4, Tel. +36 62 455 133, Fax +36 62 312 529	4	5	194/12		201/14		228/12		346/15		284/14	
Szombathely: Markusovszky Hospital, H-9007 Markusovszky u. 3, Tel. +36 94 311 542, Fax +36 94 327 873	0	3	20		64		51		42		38	
Zalaegerszeg: County Hospital, H-8901, P.O. Box 24, Tel. +36 94 311 410 (ext. 1580)	1	4	166		121		130		116		111	

CVS = Chorionic villus sampling; AC = amniocentesis.

Molecular and/or biochemical genetic laboratories in Hungary

	Number of staff		Diseases studied	Number of exams and pathological outcomes				
	MD	others		1990	1991	1992	1993	1994
Budapest: Buda Children's Hospital, Screening Centre of Congenital Metabolic Disorders, PKU Laboratory, H-1277 P.O. Box 14, Tel. +36 1 212 41 47, Fax +36 1 212 52 52	1	3	total PKU galactosaemia biotinidase deficiency hypothyroidism	62,040 3 1 2 24	63,120 8 1 2 15	61,000 8 0 4 13	59,663 10 3 1 23	57,120 6 1 5 27
Budapest: Department of Biochemistry, HHH, H-1097 Gyáli út 2-6., Tel. +36 1 215 22 50, Fax +36 1 215 01 48, E-Mail HI889 VIN@ELLA HU	1	2	spinal muscular atrophy, infantile (Werdnig-Hoffmann)	0	3/0	4/0	12/3	6/1
Budapest: Semmelweis University of Medicine, Department of Internal Medicine III, H-1121 Eötvös út 12, Tel. +36 175 45 33	1	2	MCAD deficiency familial hypercholesterolaemia familial defective apoB ApoE polymorphism ACE I/D polymorphism ApoA IV 1/2 polymorphism	-	-	-	-	1,400/5 2/1 230/3 250 20 30
Budapest: National Institute of Oncology, H-1525 Ráth Gy. u. 7-9, Tel. +36 1 155 01 25, Fax +36 1 156 24 02	2	4	familial breast and ovarian cancer (BRCA1, BRCA2)	-	-	-	-	6/4
Budapest: National Institute of Haematology, Blood Transfusion and Immunology, H-1113 Daróczi út 24, Tel. +36 1 166 58 22, Fax +36 1 166 60 04								
Thalassaemia	2	4	thalassaemia	50/15	42/17	38/12	21/9	0/0
Haemophilia	2	4	haemophilia	-	-	-	-	15
Immunogenetics	3	6	HLA (transplantation)	170	140	255	351	462
Molecular genetics	1	1	microsatellite (leukaemia-lymphoma)	60/28	143/57	270/88	436/150	464/148
Budapest: Semmelweis University of Medicine, Department of Paediatrics II, H-1094 Tűzoltó u. 7-9, Tel. +36 1 215 13 80, Fax +36 1 217 57 70, E-Mail: fekgyo@gyer2.sote.hu	2	1	cystic fibrosis antenatal microsatellite congenital adrenal hyperplasia Wilms tumour/aniridia	81/8 - - - -	113/66 - - - -	366/122 9/2 - - -	368/73 11/2 - - -	506/189 11/4 7/4 7/6 93
Budapest: I. Department of Obstetrics and Gynaecology, Semmelweis University Medical School, H-1088 Baross u. 27, Tel. +36 1 210 03 15, Fax +36 1 114 02 31	4	4	cystic fibrosis, haemophilia, colon polyposis, Werdnig-Hoffmann, adult polycystic kidney, Huntington disease	3/0	6/1	11/2	10/3	12/2

Molecular and/or biochemical genetic laboratories in Hungary (continued)

	Number of staff		Diseases studied	Number of exams and pathological outcomes				
	MD	others		1990	1991	1992	1993	1994
Debrecen: University Medical School, Department of Obstetrics and Gynaecology, H-4012 Nagyerdei krt. 98, Tel. +36 52 417 144, Fax +36 52 417 577	10	4	Duchenne	-	-	-	2	2
Debrecen: University Medical School, Department of Clinical Chemistry, H-4012, Tel./Fax +36 52 417 631	1	1	deletion screening, Duchenne, Becker, Limb-girdle muscular dystrophy, muscular dystrophy of unknown origin	-	-	36/15	28/9	24/8
Debrecen: University Medical School, Department of Neurology, H-4012, Tel./Fax +36 52 415 176	1	1	dystrophin	-	-	-	22/10	28/12
Pécs: University Medical School, Department of Paediatrics, Division of Genetics, H-7623 József A. u. 4, Tel. +36 72 310 144, Fax +36 72 314 937	3	4	cystic fibrosis, myopathies, haemophilia, lysosomal and mitochondrial amino acids, organic acid diseases	41/5	30/3	46/13	210/22	270/34

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Ireland

Departments, Centres and Institutions Involved in Genetic Services

No information is available.

Workloads

Tests offered by the molecular genetics laboratory, National Centre for Medical Genetics, November, 1996

Disorder	Tests offered	Basis of test(s)
Duchenne/Becker muscular dystrophy	diagnostic deletion screen, carrier detection and prenatal diagnosis	multiplex PCR for deletions; linked markers; PTT for mutations
Cystic fibrosis	diagnostic mutation screen, carrier detection and prenatal diagnosis	direct mutation detection for the 11 most common Irish mutations
Fragile X syndrome	diagnosis, carrier detection and prenatal diagnosis	expansions by Southern blot and direct sizing of (CCG) _n repeat by PCR
Prader Willi syndrome	diagnosis	Southern blot for both deletions and disomy; microsatellite markers to distinguish the two
Angelman syndrome	diagnosis	Southern blot for both deletions and disomy; microsatellite markers to distinguish the two
Huntington disease	diagnostic testing	direct sizing of (CAG) _n repeat by PCR
Myotonic dystrophy	diagnosis, predictive testing, prenatal diagnosis	expansions by Southern blot and direct sizing of (CTG) _n repeat by PCR
Familial adenomatous polyposis coli	predictive testing	direct mutation detection, linked and intragenic markers
Hereditary non-polyposis colon cancers	diagnosis and predictive testing	direct mutation detection, linked and intragenic markers
Multiple endocrine neoplasia and associated <i>RET</i> disorders	diagnosis, predictive testing	direct mutation detection
Spinal muscular atrophies	diagnosis	deletion detection, linked markers
Silver-Russell syndrome and primordial growth retardation	uniparental disomy testing	microsatellite analysis of parents and child

Patient Organisations

Inherited Diseases Organisation
(Hon. Sec. Mrs. Julia M. Windle)
Carmichael House
North Brunswick Street
Dublin 7
Tel. +353 1 872 1501, Fax +353 1 872 4482

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Israel

Departments, Centres and Institutions Involved in Genetic Services

- Hadassah Medical Centre Jerusalem
Department of Human Genetics
Cytogenetics, biochemical and molecular genetics
Gideon Bach, PhD
Tel. +972 2 6776931, Fax +972 2 6777499
E-Mail bach@cc.huji.ac.il
- Beilinson Hospital, Rabin Medical Centre, Petach Tiqva
Institute of Medical Genetics
Cytogenetics, biochemical genetics and molecular genetics
Mordechai Shohat, MD
Tel. +972 3 9377658, Fax +972 3 9377660
- Bnai Zion Medical Centre, Haifa
Simon Winter Institute for Human Genetics
Cytogenetics, biochemical and molecular genetics
Zvi Borochowitz, MD
Tel. +972 4 359459, Fax +972 4 371393
- Ichilov Hospital, Tel Aviv
Genetic Institute
Cytogenetics, biochemical and molecular genetics
C. Legum, MD
Tel. +972 3 6974703, Fax +972 3 6974555
- Haemek Hospital, Afula
Genetic Unit
Cytogenetics
H. Cohen, PhD
Tel. + 972 6 524345, Fax + 972 6 522642
- Herzlia Medical Centre, Herzlia
Genetic Unit
Cytogenetics
- Rambam Medical Centre, Haifa
Genetic Unit
Cytogenetics, biochemical and molecular genetics
R. Gershoni-Baruch, MD
Tel. +972 4 542456, Fax +972 4 515710
- Kaplan Hospital, Rehovot
Clinical Genetic Unit
Cytogenetics, biochemical and molecular genetics
Z. Gleman-Kohan, MD
Tel. +972 8 944 1384, Fax +972 8 941 0991
- Meir Hospital, Kfar Sava
Genetic Unit
Cytogenetics and biochemical genetics
O. Reish, MD
Tel. +972 9 900 253
- Asaf Harofe, Tsrifin
Genetics Unit
Cytogenetics, biochemical genetics
K. Fried, MD, PhD
Tel. +972 8 977 9745
- Sheba Medical Centre, Tel Hashomer
Department of Human Genetics
Cytogenetics, biochemical and molecular genetics
B. Goldman, MD
Tel. +972 3 5302826, Fax +972 3 5302914
- Soroka Medical Centre, Beer Sheva
Genetic Institute
Cytogenetics, biochemical and molecular genetics
R. Carmi, MD
Tel. +972 7 400907, Fax +972 7 280955

Wolfson Medical Centre, Holon
Genetic institute
Cytogenetics

Workloads

No information is available.

Patient Organisations

No information is available.

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Italy

Numbers of Staff Involved in Medical Genetic Service Provision

No information is available

Departments, Centres and Institutions Involved in Genetic Services

From 1996 census (held by the Italian Genetic Scientific Societies): 250 genetic counselling centres, 62 molecular diagnostic laboratories and 116 cytogenetic laboratories.

Workloads

No information is available.

Patient organisations

More than 200 patient/family organisations are active. See the Internet www.genet.it.

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Latvia

Departments, Centres and Institutions Involved in Genetic Services

- State Medical Genetics Centre
State Children Clinical Hospital 'Gailezers'
20 Juglas str
LV-1038 Riga
Tel. +371 2 536840, 536672
- Department of Medical Biology and Genetics
Medical Academy of Latvia
16 Dzirciema str
LV-1007 Riga
Fax +371 7 828155
- A. Kirhenstein Institute of Microbiology and Virology
1 Kirhemsteina str
LV-1067 Riga
Tel. +371 2 428038, Fax +371 2 428036

University of Latvia
Biomedical Research and Study Centre
1 Kirhensteina str
LV-1067, Riga
Fax +371 2 427521

Association of Latvian Medical Geneticists
Department of Medical Biology and Genetics
Medical Academy of Latvia
Dzirciema str. 16
LV-1007 Riga
Fax +371 7 828155

Workloads

No information is available.

Patient Organisations

National Society for PKU
Latvian State Medical Genetics Centre
Juglas 20
LV-1038 Riga
Tel. +371 2 53 68 40, Fax +371 2 53 66 72

National Society for Down Syndrome
Putnu 2 apt. 79
LV 2016 Jurmala

National Society for CF
Prusu 3/2, apt. 42
LV-1065 Riga
Tel. 251 710

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Lithuania

Departments, Centres and Institutions Involved in Genetic Services

Structure of the Human Genetics Centre

- 1.1 Genetic Counselling Clinic
- 1.2 Mass Neonatal Screening Unit
- 1.3 Lithuanian Registry of Inherited Diseases and Congenital Anomalies (LIRECA)
- 1.4 Laboratory Unit
 - 1.4.1 Laboratory of Biochemistry
 - 1.4.2 Laboratory of Molecular Genetics
 - 1.4.3 Laboratory of Cytogenetics
- 1.5 Computer Unit

Workloads

No information is available.

Patient Organisations

No information is available.

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The Netherlands

Departments, Centres and Institutions Involved in Genetic Services

Department of Clinical Genetics
Academic Hospital Vrije Universiteit
Postbus 7057
1007 MB Amsterdam
Tel. +31 20 444 0150, Fax +31 20 444 0769

Department of Clinical Genetics
Academic Medical Centre
Meibergdreef 15
1105 AZ Amsterdam
Tel. +31 20 566 5111, Fax +31 20 601 8626

Department of Medical Genetics
University of Groningen
A. Deusinglaan 4
9713 AW Groningen
Tel. +31 50 363 2925, Fax +31 50 363 2947

Department of Clinical Genetics
Academic Hospital Leiden
Postbus 9600
2300 RC Leiden
Tel. +31 71 526 8033, Fax +31 71 524 8109

Department of Clinical Genetics
Postbus 1475
6201 BL Maastricht
Tel. +31 43 387 5855, Fax +31 43 3877 7877

Department of Clinical Genetics
St. Radboud Hospital
Postbus 9109
6500 HB Nijmegen
Tel. +31 24 361 3947, Fax +31 24 356 5026

Department of Clinical Genetics
Erasmus University
Westzeedijk 112
3016 AH Rotterdam
Tel. +31 10 463 6918, Fax +31 10 436 0146

Centre for Clinical Genetics
Postbus 18009
3501 CA Utrecht
Tel. +31 30 232 0310, Fax +31 30 232 0282

Workloads

No information is available.

Patient Organisations

V.S.O.P.
Vredehotstraat 31
3761 HA Soestdyk
Tel. +31 35 602 8155, Fax +31 35 602 7440

Norway

Numbers of Staff Involved in Medical Genetics Service Provision in the Author's Centre

Department of Medical Genetics, Regional Hospital, Tromsø

Population served	Genetically trained physicians	Genetic physicians in training	Cytogenetically or molecularly trained technicians	Trained molecular geneticists	Genetic nurses
475,000	1	2	9	3	1

Departments, Centres and Institutions Involved in Genetic Services

Institute of Medical Genetics

University of Oslo
with Department of Medical Genetics, Ullevål Hospital
PO Box 1036, Blindern
N-0315 Oslo
Tel. +47 22 11 98 60, Fax +47 22 11 98 99

Institute of Medical Genetics

University of Bergen
with Department of Medical Genetics, Haukeland Hospital
N-5021 Bergen
Tel. +47 55 97 54 75, Fax +47 55 97 54 79
E-Mail helge.boman@gen.haukeland.no

Department of Medical Genetics

Regional Hospital of Tromsø
PO Box 55
N-9038 Tromsø
Tel. +47 77 64 54 10, Fax +47 77 64 54 30
E-Mail lisbeth@fagmed.uit.no

Department of Genetics

Section of Molecular Pathology
The Norwegian Radium Hospital
Montebello
N-0310 Oslo
Tel. +47 22 93 56 77, Fax +47 22 93 44 40
E-Mail sverre.heim@labmed.uio.no, all@radium.uio.no

Unit of Medical Genetics

Department of Oncology
The Norwegian Radium Hospital
Montebello
N-0310 Oslo
Tel. +47 2293 4420, Fax +47 2293 5219
E-Mail pmoller@labmed.uio.no

Genetic Section

Department of Occupational and Environmental Medicine
Telemark Central Hospital
N-3710 Skien
Tel. +47 35 58 31 47, Fax +47 35 58 31 05
E-Mail inger-lise.hansteen@tss.telemax.no

Biochemical Genetics Paediatric Research Laboratory

University Hospital
PO Box 1036, Blindern
N-0315 Oslo
Tel. +47 22 11 98 60, Fax +47 22 11 98 99

Department of Clinical Chemistry

University Hospital (Rikshospitalet)
Pilestredet 32
N-0027 Oslo
Tel. +47 22 86 70 10, Fax +47 22 86 70 29

Workloads

	Department of Medical Genetics Ullevål	Department of Medical Genetics Haukeland (1994)	Department of Medical Genetics Tromsø (1994)	The Norwegian Radium Hospital (cancer research)	Genetic Section Department of Occupational and Environmental Medicine	Total (1993)
Cytogenetic	1,503 (1994)	670 (1994)	681	320 (1994) tumour cytogenetic	155 (1994)	-
Amnio/ CVS	1,024/36 (1993) ^b	215/7 (1994) ^c	118/-	-/-	-/-	-
Molecular genetic analysis	617 (1994)	512 (1994)	860	339 (1994)	-	
Number of genetic counsellings (patient consultations)						
Prenatal	-	258 (1994)	152	-		
Others	433 (1994) ^d	107 (1994)	112	683 (1994)		

^a Source: Annual Report from Haukeland Hospital. The figures were confirmed by the head of the Department for Medical Genetics, Professor Helge Boman.

^b In 178 amnios, taken at the Regional Hospital in Trondheim, the females were counselled locally.

^c In this compilation 3 cordocenteses are included.

^d Source: Annual Report from Ullevål Hospital.

Patient Organisations

There are a large variety of patient organisations. Information can be obtained at all the regional Departments of Medical Genetics, at Frambu Center and at Smågruppenteret at the University Hospital, tel. +47 22 86 70 10.

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Poland

Departments, Centres and Institutions Involved in Genetic Services

Centre name	Population served	Genetically trained physicians	Genetic physicians in training	Cyto-geneticists	Molecular geneticists	Genetic co-workers
1 Department of Biology and Genetics, Medical School of Gdansk, Fax +48 58 316 115	2,370,000	2	1	7	2	-
2 Department of Medical Genetics, Medical School of Poznan, Fax + 48 61 48 33 62	3,700,000	4	2	2	1	-
3 Department of Human Genetics, Polish Academy of Sciences, Poznan, Fax +48 61 23 32 35	same population as No. 2	2	-	4	11	-
4 Department of Medical Genetics, Polish American Institute, Medical School, Jagiellonian University of Krakow, Fax +48 12 58 44 46	6,000,000	2	1	4	2	1
5 Department of Medical Genetics, Medical School of Lodz, Fax +48 42 36 54 27	4,500,000	6	-	7	3	3
6 Department of Genetics, Child Health Centre - Institute, Warszawa, Fax +48 154 015	774,000	3	-	7	5	2
7 Department of Genetics, Institute of Mother and Child, Warszawa, Fax +48 329 454	356,000	3	-	5	4	1
8 Department of Genetics, Institute of Psychiatry and Neurology, Warszawa, Fax +48 642 53 75	985,000	3	-	3	3	1

Based upon the definition of a 'genetic centre' by Prof. R. Harris. No. 6-8 provide services on a national level (patients are referred from all regions of the country). As regards provision of prenatal diagnosis in the city and the province of Warsaw, they work on a regional basis.

Workloads

No information is available.

Patient Organisations

There are many patient organisations for different genetic disorders, such as Down syndrome, Turner syndrome, cystic fibrosis, mucopolysaccharidoses, tuberous sclerosis and neuromuscular disorders.

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Portugal

Departments, Centres and Institutions Involved in Genetic Services

In Portugal it is impossible to know the exact number of workers in the field of genetics, but as far as the authors know the most relevant centres currently working in genetics are given here.

Serviço de Genética Médica

Hospital Egas Moniz, Ministry of Health, Lisbon
 Clinical genetics, cytogenetics, National Registry of Congenital Anomalies
 Staff: clinical genetics - 1, non-medical laboratory geneticist - 3, graduate - 1, technician - 2
 Cytogenetic studies - 488 (including prenatal)
 Patient clinics - 687

Centro de Metabolismos e Genética

Faculdade de Farmácia de Lisboa, Ministry of Education, Lisbon
 Biochemistry, molecular genetics, teaching (biochemistry), research (inborn errors of metabolism)
 Staff: paediatrician - 3, researcher - 19, graduate - 3, technician - 2
 Biochemical Studies: 1,900

Unidade de Genética

Hospital D. Estefania, Ministry of Health, Lisbon
 Clinical genetics, biochemistry, pregraduate and postgraduate teaching
 Staff: clinical geneticist - 1, paediatrician - 1, technician - 1
 Biochemical studies: 422
 Patient clinics: 3,350

Unidade de Genética

Serviço de Pediatria, Hospital Santa Maria, Ministry of Health, Lisbon
 Clinical genetics and cytogenetics; pregraduate teaching (Faculdade de Medicina - Universidade de Lisboa) and postgraduate teaching
 Staff: clinical geneticist - 3, technician - 2
 Cytogenetic studies: 160 (peripheral blood)
 Patient clinics: 735

Instituto Dr. Ricardo Jorge, Ministry of Health

Departamento de Genética Humana, Lisbon
 Cytogenetics, molecular biology, research (carcinogenesis, mutagenesis, DNA repair, cystic fibrosis, blood disorders, sex differentiation disorders, chromosome aberrations)
 Staff: researcher - 4, graduate - 4, technician - 5
 Cytogenetic studies: 1,500 (including prenatal)
 DNA samples: 518

Departamento de Genetica

Universidade Nova de Lisboa, Ministry of Education, Lisbon
Cytogenetics, biochemistry, molecular genetics, pregraduate teaching, research (mutagenesis, oncogenesis, cancer-prone genetic diseases)
Staff: medical laboratory geneticist – 4, non-medical laboratory geneticist – 19, researcher – 18
Laboratory studies: 150

Instituto Dr. Ricardo Jorge, Ministry of Health

Departamento de Biologia Medica, Lisbon
Biochemistry, molecular biology, teaching (postgraduate laboratory technicians), research (metabolic diseases, haemoglobinopathies), National Registry of Haemoglobinopathies
Staff: researcher – 3, graduate – 2, technician – 5
Haemoglobin studies: 3,816
Biochemical studies: 353
G6PD studies: 260

Consulta de Genetica

Hospital Pediátrico, Ministry of Health, Coimbra
Clinical genetics
Staff: clinical geneticist – 1
Molecular studies: 132
Patient clinics: 303

Serviço de Genetica Medica

Faculdade de Medicina da Universidade de Coimbra, Ministry of Education, Coimbra
Cytogenetics, molecular genetics and pre- and postgraduate teaching, research (fragile X, carcinogenesis)
Staff: medical doctor – 3 (1 clinical geneticist: J. Saraiva), technician – 1
Molecular studies: 1,432

Instituto de Biologia Medica

Faculdade de Medicina da Universidade de Coimbra, Ministry of Education, Coimbra
Cytogenetics, postgraduate teaching
Staff: clinical geneticist – 1, non-medical laboratory geneticist – 1, researcher – 1, graduate – 3, technician – 2
Cytogenetic studies: 614 (including prenatal)

Serviço de Genetica Medica

Faculdade de Medicina da Universidade do Porto, Ministry of Education, Porto
Clinical genetics, cytogenetics, molecular genetics, pre- and postgraduate teaching, research (cystic fibrosis, polycystic kidney disease)
Staff: clinical geneticist – 6, paediatrician – 2, medical laboratory geneticist – 3, non-medical laboratory geneticist – 3, graduate – 1, technician – 10
Cytogenetic studies: 1,433 (including prenatal)
Patient clinics: 2,065

Unidade de Genetica IPATIMUP

Faculdade de Medicina da Universidade do Porto, Ministry of Education, Porto
Cytogenetics, molecular genetics, pre- and postgraduate teaching, research (cancer cytogenetics and molecular biology, Prader-Willi, Angelman syndrome)
Staff: clinical geneticist – 1, medical laboratory geneticist – 5, researcher – 3, graduate – 3, technician – 2
Cytogenetic studies: 1,028
Molecular studies: 260

Instituto de Genetica Medica (IGM), Ministry of Health, Porto

Clinical genetics, cytogenetics, molecular genetics, postgraduate teaching, research (molecular and biochemical studies on metabolic diseases including mitochondrial diseases), National Newborn Screening Programme
Staff: clinical genetics – 2, paediatrician – 1, medical laboratory geneticist – 2, researchers – 5, graduate – 10, technician – 21
Cytogenetic studies: 1,418
Patient clinics: 3,185
Molecular genetics: 1,837
Enzymes: 9,501
Biochemical studies: 8,286
Newborn screening: 219,809

Laboratorio de Genetica Medica (ICBAS)

Universidade do Porto, Ministry of Education, Porto
Pre- and postgraduate teaching and research (Machado Joseph disease)
Staff: clinical genetics – 1, neurologist – 1, researcher – 6

Consulta de Genetica

Hospital D. Maria Pia, Ministry of Health, Porto
Clinical genetics, postgraduate teaching
Staff: clinical geneticist – 1
Patient clinics: 586

Centro de Genetica Clinica e Patologia, Porto (private)

Clinical genetics, cytogenetics, biochemistry, molecular genetics
Staff: clinical geneticist – 2, non-medical laboratory geneticist – 8
Cytogenetic studies: 1,190 (including prenatal)

Patient Organisations

Down syndrome, cystic fibrosis, neural tube defects, osteogenesis, haematological diseases, metabolic diseases, neuromuscular diseases and others. In recent years, genetic patients' organisations and the media have made an important contribution to education.

Romania

Numbers of Staff Involved in Medical Genetic Service Provision

No information is available.

Departments, Centres and Institutions Involved in Genetic Services

No information is available.

Workloads

No information is available.

Patient Organisations

No information is available.

Russia

Numbers of Staff Involved in Medical Genetic Service Provision

Genetically trained physicians: 300

Genetic physicians in training: 60

Cytogeneticists: 215

Molecular geneticists: 50

Departments, Centres and Institutions Involved in Genetic Services

Federal Medical Genetic Centres

- Research Centre for Medical Genetics
Moskvorechie 1
RUS-5478 Moscow II
Tel. +7 095 111 85 80, Fax +7 095 324 07 02
- Research Institute for Medical Genetics poselok
RUS-634058 Sputnik Tomsk
Tel. +7 3822 22 22 28, Fax +7 3822 22 37 44
- Laboratory prenatal diagnosis of inherited disorders
Institute of Obstetrics and Gynaecology
Mendeleevskaya line 3
RUS-199034 St. Petersburg
Tel./Fax +7 812 218 04 87, Fax +7 812 218 23 61
- Department of Clinical Genetics,
Research Institute of Paediatrics and Infant Surgery
Taldomskaya 2
Moscow
Tel. +7 095 487 42 79, Fax +7 095 483 33 35
- Research Centre of Perinatology, Obstetrics and Gynaecology
Oparina 4
RUS-117815 Moscow
Tel. +7 095 438 24 11, Fax +7 095 438 49 65
- Children's Psychiatric Clinic No. 6
5 Donskoy Pr. 21a
RUS-117334 Moscow
Tel. +7 095 954 37 67, Fax +7 095 952 51 51
- Medical Genetics Department
Medical Stomatological Institute
Delegatskaya st 20
RUS-103473 Moscow
Tel. +7 095 113 96 66

Workloads

Monogenic disorders amenable to molecular diagnosis

Cystic fibrosis: SP, M, T, N
Duchenne muscular dystrophy: SP, M, T
Haemophilia a: SP, M
Haemophilia b: SP, M
PKU: SP, M, T
Fragile X-A and X-B: SP, M
Myotonic dystrophy: SP
Huntington disease: SP, M
Kennedy disease: SP
von Willebrand disease: SP, M
Friedreich ataxia: M
Spinal muscular atrophy: M
Lesch-Nyhan syndrome: SP
Hunter syndrome: SP, M
Familial hypercholesterolaemia: SP
Stunted death syndrome: SP
 β -Thalassaemia: SP, M
Antitrypsin deficiency: SP
Type I diabetes predispositions: SP
Alport syndromes: M
Adrenogenital syndrome: M
Charcot-Marie-Tooth: M
Hepatolenticular degeneration (Wilson disease): M

SP = St. Petersburg; M = Moscow; T = Tomsk; N = Novosibirsk.

Number of diagnostic samples analysed in 1994

Samples	Genetic Counselling Units	Federal Medical Genetics Centres
<i>Cytogenetics</i>		
Karyotypes		
Postnatal	23,000	1,700
Prenatal	590	820
<i>Molecular genetics</i>		
Analysis		
Postnatal	-	1,000
Prenatal	-	100
<i>Biochemical genetics</i>		
Postnatal	740,000	95,000
Prenatal	-	140
<i>Genetic consultation</i>		
Primary	79,730	16,500
Secondary	78,750	10,200

Patient Organisations

Federal Cystic Fibrosis Association
Federal Neuromuscular Disorders Association
All-Russian Association of Invalids
Association of Parents and Disabled Children Suffering from Illnesses of Adrenals: 'Second Life'

Serbia

Departments, Centres and Institutions Involved in Genetic Services

- Centre for Medical Genetics
Institute of Health Care for Children
Novi Sad
- Institute of Biology and Human Genetics
Faculty of Medicine
Belgrade
- Faculty of Stomatology
Institute
Belgrade
- Institute for Mental Health
Genetic Department
Belgrade
- Mother and Child Institute
Genetic Department
New Belgrade
- Zvezdara Medical Centre
Belgrade

Workloads

No information is available.

Patient Organisations

Cystic Fibrosis Association, Association of Invalids, Association of Diabetic Patients

Slovenia

Numbers of Staff Involved in Medical Genetic Service Provision

Centre name	Genetically trained physicians	Physicians in genetic training	Cyto-geneticists	Molecular geneticists	Genetic nurses/counselors
<i>Laboratories</i>					
Division of Medical Genetics, Department of Obstetrics and Gynaecology, University Medical Centre, Ljubljana	2	2	2	2 + 3 ^a	0
Department of Medical Genetics, Institute of Public Health, Republic of Slovenia	1	0	1	0	0
Department for Laboratory Diagnostics and Mutagenesis, Institute of Occupational Safety	0	0	1	0	0
Cytogenetics Laboratory, Maribor	0	0	2	0	0
Institute of Prenatal and Postnatal Diagnosis	1	0	1	0	0
<i>Molecular genetic laboratories</i>					
Laboratory for Molecular Pathology, Institute of Pathology, Medical Faculty	0	0	0	2 ^a	0
Institute of Biochemistry, Medical Faculty	1 ^b	0	0	5 ^a	0
Blood Transfusion Center of Slovenia, Tissue Typing Centre ^c	0	0	0	2	0
Laboratory of Haemogenetics, Institute of Forensic Medicine, Medical Faculty ^d	1 ^e	0	0	1	0

^a Staff that are only involved part time in providing genetic services employed by the Slovene Ministry of Science and Technology or Medical Faculty, Ljubljana.

^b Trained in molecular genetics.

^c Involved only in HLA genotyping.

^d Involved only in legal identification DNA procedures.

^e Specialist of pathology, additionally trained in legal identification DNA procedures.

Departments, Centres and Institutions Involved in Genetic Services

Division of Medical Genetics
 Department of Obstetrics and Gynaecology
 UMCL, Ljubljana
 Tel. +386 61 14 01 137, Fax +386 61 315 328
 E-Mail borut.peterlin@gest.arnes.si

Department of Medical Genetics
 Institute of Public Health
 Ljubljana
 Tel. +386 61 312 462

Cytogenetic Laboratory
 Maribor Teaching Hospital
 Maribor
 Tel. +386 62 37 221/38, Fax +386 62 35 136

Department for Laboratory Diagnostic and Mutagenesis
 Institute of Occupational Safety
 Ljubljana
 Tel. +386 61 132 02 53/277, Fax +386 61 312 562

Institute for Prenatal and Postnatal Diagnosis
 Postojna
 Tel. +386 67 24 758, Fax +386 67 24 758

Institute of Biochemistry
 Medical Faculty of Ljubljana
 Ljubljana
 Tel. +386 61 132 00 19, Fax +386 61 132 00 16
 E-Mail komel@ibmi.mf.uni-lj.si

Laboratory for Molecular Pathology
 Institute of Pathology
 Medical Faculty Ljubljana
 Tel. +386 61 316 277, Fax +386 61 301 816
 E-Mail glavac@ibmi.mf.uni-lj.si

Laboratory for Haemogenetics
 Institute of Forensic Medicine
 Medical Faculty Ljubljana
 Tel. +386 61 443 903, Fax +386 61 443 864

Blood Transfusion Center of Slovenia
 Tissue Typing Centre
 Ljubljana
 Tel. +386 61 302 313, Fax +386 61 13 304
 E-Mail matjaz.jeras@ibmi.mf.uni-lj.si

Workloads

Number of genetic counselling and diagnostic samples analysed in 1995 (January 1–December 31) or 1996 (January 1–November 1)

Centre/laboratory	Investigation					
	genetic counselling		cytogenetics		molecular genetics	
	general	prenatal	postnatal	prenatal	general	prenatal
Division of Medical Genetics, Department of Obstetrics and Gynaecology, University Medical Centre, Ljubljana	217	781	272	781	97	3 + 11 ^a
Cytogenetic Laboratory Maribor	–	–	164	44	–	–
Department of Medical Genetics, Institute of Public Health	–	–	283	–	–	–
Department for Laboratory Diagnostic and Mutagenesis, Institute of Occupational Safety	–	–	972	–	–	–
Institute of Biochemistry, Medical Faculty	–	–	–	–	67	9
Laboratory for Molecular Pathology, Institute of Pathology, Medical Faculty	–	–	–	–	7	1
Blood Transfusion Centre of Slovenia, Tissue Typing Centre	–	–	–	–	450 ^b	–
Laboratory for Haemogenetics, Institute of Forensic Medicine, Medical Faculty	–	–	–	–	29 ^c	–

^a Organised in collaboration with centres from abroad.

^b DNA – HLA genotyping.

^c DNA identification procedures.

Patient Organisations

No information is available.

Spain

Departments, Centres and Institutions Involved in Genetic Services, 1996

Autonomous community (population served)	Centre/unit name and address	Genetically trained physicians	Genetically trained scientists	Geneticists in training
Andalucia (7,000,000)	Hospital Reina Sofia, Avda. Menendez Pidal, s/n, E-14004 Cordoba, Tel. +34 57 217000, Fax +34 57 202542	1	0	0
	Hospital Universitario, Avda. Oloriz, 16, E-18012 Granada, Tel. +34 58 270200	3	0	0
	H. Virgen de las Nieves, Avda. Fuerzas Armadas, E-13014 Granada, Tel. +34 58 241110, Fax +34 58 283147	2	0	0
	Hospital Materno-Infantil, Arroyo de los Angeles s/n, E-29011 Málaga, Tel. +34 58 2304400, Fax +34 58 2275763	3	0	0
	Hospital Universitario V. Macarena, Sanchez Pizjuan, s/n, E-41009 Sevilla, Tel. +34 5 4901873, Fax +34 5 4371284	2	0	0
	Hospital Universitario V. Rocio, Manuel Siurot, s/n, E-41013 Sevilla, Tel. +34 5 4248009, Fax + 34 5 4388111	2	1	2
	Aragon (1,200,000)	Hospital Clínico Universitario, San Juan Bosco, 15, E-50009 Zaragoza, Tel. + 34 76 556400	2	0
Hospital Miguel Servet, Plaza Isabel la Católica 1 & 3, E-50009 Zaragoza, Tel. +34 76 354316, Fax + 34 76 351893		4	6	1
Asturias (1,100,000)	Hospital Central Asturias, Celestino Villasmil, s/n, E-33006 Oviedo, Tel. + 34 8 108000, Fax +34 8 108015	4	1	0
Balears (700,000)	Hospital Son Dureta, Avda. Andrea Doria, 55, E-07014 Palma de Mallorca, Tel. + 34 71 175000, Fax + 34 71 175500	1	1	1
	C. Detección Precoz & C. Genético, Cecilio Melero, 18, E-07003 Palma de Mallorca, Tel. + 34 71 726860, Fax +34 71 718701	2	0	0

Departments, Centres and Institutions Involved in Genetic Services, 1996 (continued)

Autonomous community (population served)	Centre/unit name and address	Genetically trained physicians	Genetically trained scientists	Geneticists in training
Canarias (1,500,000)	Hospital Materno Infantil, Avda. Marítima, s/n, E-35016 Las Palmas, Tel. +34 28 321222	1	2	0
	Facultad de Medicina, Campus de Ofra. Carr La Cuesta-Taco, E-37071 La Laguna, Tenerife, Tel. +34 22 603450, Fax +34 22 603407	2	1	1
Cantabria (525,000)	Hospital Valdecilla, Valdecilla, E-39011 Santander, Tel. +34 42 202520, Fax +34 42 202720	3	0	0
Castilla-La Mancha (1,700,000)	Hospital Nacional de Paraplégicos, La Perelada, s/n, E-45071 Toledo, Tel. +34 25 269310, Fax +34 25 216612	1	1	4
Cataluña (6,000,000)	Instituto Bioquímica Clínica, C/ Mejía Lequerico, s/n, Edificio Helios planta baja, E-08028 Barcelona, Tel. +34 3 227 5600, Fax +34 3 227 5668	1	13	7
	H. Materno-Infantil Vall d'Hebron, P. Vall d'Hebron, 119-129, E-08035 Barcelona, Tel. +34 3 4272000, Fax +34 3 4282171	2	4	0
	H. de la Santa Creu i Sant Pau, Padre Claret 167, E-08025 Barcelona, Tel. +34 3 2919361, Fax +34 3 2919192	1	5	8
	Hospital Clínic, Villarroel 170, E-08036 Barcelona, Tel. +34 3 2275510, Fax +34 3 2275454	3	6	6
	Instituto Resercha Oncologica, Autovía Castelfells, Km 2,7, E-08907 Hospitalet, Tel. +34 3 3357152, Fax +34 3 2632251	2	7	20
	Consorci Hospitalari Parc Tauli, Parc Tauli, E-08208 Sabadell, Tel. +34 3 285400	1	1	3
Galicia (2,700,000)	H. Materno-Infantil Teresa Herrera, Avda. del Pasaje s/n, E-15006 La Coruña, Tel. +34 81 285400	1	2	0
	Centro Oncológico de Galicia, Avda. Monserrat, s/n, E-15006 La Coruña, Tel. +34 81 287499, Fax +34 81 287122	1	1	0
	H. General de Galicia & H. Gil Casas, Galera, s/n, E-15705 Santiago de Compostela, Tel. +34 81 570122	2	0	0
Madrid (5,000,000)	Fundación Jimenez Diaz, Avda. Reyes Católicos, 2, E-28040 Madrid, Tel. +34 1 5449223, Fax +34 1 5494764	1	4	6
	Hospital Ramón y Cajal, Ctra. Colmenar, Km 9,100, E-28034 Madrid, Tel. +34 1 3368334/3368541, Fax +34 1 3369016	7	4	6
	Hospital La Paz, Paseo de la Castellán, 261, E-28046 Madrid, Tel. +34 1 3582600, Fax +34 1 7291179	2	1	0
	Hospital de Móstoles, C/ Río Júcar, s/n, E-28935 Móstoles, Madrid, Tel. +34 1 6243000	0	2	0
	Hospital 12 Octubre, Carretera Andalucía, Km 5,400, E-248041 Madrid, Tel. +34 1 3908326/3908315, Fax +34 1 4603310	5	3	0
Murcia (1,000,000)	Instituto Bioquímica Clínica, Apartado de correos 61, E-31100 Espinardo, Murcia, Tel. +34 68 307227, 307239, Fax +34 68 305005	0	4	0
Navarra (500,000)	Hospital Virgen del Camino, Irunlarrea, s/n, E-31008 Pamplona, Tel. +34 48 109990, Fax +34 48 170515	2	2	4
P. Valenciano (3,900,000)	Universitat d'Alicant, Campus de Sant Joan. Apart. correos 374, E-03080 Alicante, Tel. +34 7 5903843, Fax +34 7 5903839	1	0	2
	Hospital La Fe, Campanar, s/n, E-46009 Valencia, Tel. +34 6 3822700, Fax +34 6 3868789	4	1	4
	Dpto. Patología, Universidad de Valencia, Avda. Blasco Ibañez, 17, E-46010 Valencia, Tel. +34 6 3864146, Fax +34 6 3864173	2	3	1
Pais Vasco (2,100,000)	Hospital Civil Basurto, C/ Montevideo, s/n, E-48013 Bilbao, Tel. +34 4 4416988, Fax +34 4 4425804	1	2	2
	Residencia S. Enrique Sotomayor, Plaza Cruces, s/n, Baracaldo, Vizcaya, Tel. +34 4 4903100, Fax +34 4 4992945	1	0	0
	Policlínica Guipúzcoa, Parque Miramón, 174, E-20011 San Sebastian, Tel. +34 43 462200, Fax +34 43 471109	1	1	0

Workloads

No information is available.

Patient Organisations

Asociación celiaca en España
 Asociación de la corea de Huntington en España
 Asociación española de enfermedad de Alzheimer
 Asociación española de ataxias hereditarias
 Asociación española de cardiopatías congénitas
 Asociación española de enfermedades musculares
 Asociación española de esclerodermia
 Asociación española de la lucha contra la hipertensión
 Asociación española de lupus
 Asociación española del síndrome de Sjogren
 Asociación española para el estudio de la distonías
 Asociación española de esclerosis múltiple
 Asociación española para el síndrome de Prader-Willi
 Asociación española de la lucha contra la epilepsia
 Asociación española para pacientes con tics y síndrome de la

Tourette

Asociación española de espondilitis anquilosante
 Asociación de asociados de psoriasis
 Federación española de fibrosis quística
 Federación española de diabetes
 Federación española de retinosis pigmentaria
 Parkinson en España
 Sociedad española para la investigación y estudio de la espina

bífida

Department of Clinical Genetics
 Karolinska Hospital
 S-17176 Stockholm
 Tel. +46 8 5177 0000, Fax +46 8 5177 3926

Department of Clinical Genetics
 University Hospital
 S-90185 Umeå
 Tel. +46 90 10 1000, Fax +46 90 12 8163

Department of Clinical Genetics
 Academic Hospital
 S-75185 Uppsala
 Tel. +46 18 66 3000, Fax +46 18 55 4025

University departments of medical genetics

Department of Medical Genetics
 Uppsala University
 S-75123 Uppsala
 Tel. +46 18 17 4580, Fax +46 18 52 6849

Department of Medical Genetics
 University Hospital
 S-90185 Umeå
 Tel. +46 90 10 1320, Fax +46 90 10 3593

Clinical genetic laboratories with restricted service

Department of Clinical Genetics
 University Hospital
 S-58185 Linköping
 Tel. +46 13 22 2000, Fax +46 13 14 8156

Cytogenetic Laboratory
 Department of Pathology
 Central Hospital
 S-54185 Skövde
 Tel. +46 500 43 1000, Fax +46 500 43 8156

Other laboratories performing specialised genetic testing

PKU laboratory
 Huddinge Hospital, S31
 S-14186 Huddinge
 Tel. +46 8 746 1390, Fax +46 8 746 1395

Department of Clinical Chemistry
 Huddinge Hospital
 S-14186 Huddinge
 Tel. +46 8 746 1072, Fax +46 8 746 1698

Department of Coagulation Disorders
 Malmö University Hospital
 S-20502 Malmö
 Tel. +46 40 33 2392, Fax +46 40 33 6255

Neurochemistry Unit
 Department of Clinical Chemistry and Neurochemistry
 Mölndal Hospital
 S-43180 Mölndal
 Tel. +46 31 86 2415, Fax +46 31 2426

Department of Clinical Chemistry
 Sahlgrenska Hospital
 S-41345 Göteborg
 Tel. +46 31 60 2430, Fax +46 31 82 7610

Sweden

Numbers of Staff Involved in Medical Genetic Service Provision

Genetically trained physicians	Cyto geneticists	Molecular geneticists	Genetic counsellors
16	10 PhD hospital specialists, 80 technical staff		1

Departments, Centres and Institutions Involved in Genetic Services

Regional clinical genetic centres with specialist training

Department of Clinical Genetics
 East Hospital
 S-41685 Göteborg
 Tel. +46 31 37 4000, Fax +46 31 55 4025

Department of Clinical Genetics
 University Hospital
 S-22185 Lund
 Tel. +46 46 17 3362, Fax +46 46 13 1061

Training authorities

Socialstyrelsen (National Board of Health and Welfare)
RT-S
S-10630 Stockholm
Tel. +46 8 783 30 00, Fax +46 8 663 92 90

National union

The Swedish Medical Association
Box 5610
S-11486 Stockholm

Workloads

Hereditary disorders locally common in Sweden

Autosomal dominant disorders	Autosomal recessive disorders	X-linked disorders
Adynamia episodica hereditaria – Mb Gamstorp S	Childhood deafness N	Fragile X syndrome N Nephrogenic diabetes insipidus
Acute intermittent porphyria – Mb Waldenström N	Charcot-Marie-Tooth disease N, S	
Amelogenesis imperfecta N	Congenital myotonia – Becker type N	
Charcot-Marie-Tooth disease type 1a N	Epidermolysis bullosa hereditaria letalis – Mb Herlitz N	
Congenital dyserythropoetic anaemia type III N	Mb Gaucher type III N	
Congenital myotonia N	Haemochromatosis N	
Distal muscular atrophy – Mb Velander S	Hereditary fructose intolerance N	
Essential tremor N	Hereditary glucose-galactose malabsorption N	
Familial amyloidosis with polyneuropathy N	Infantile genetic agranulocytosis – Mb Kostman N	
Hereditary macular degeneration – Mb Best N	Olivopontocerebellar atrophy type III N	
Huntington disease N, S	Osteopetrosis N	
Hyperkeratosis palmaris et plantaris N	Progressive myoclonic epilepsy – Unvericht-Lundborg type S	
Myoclonic dystonia S	Sjögren-Larsson syndrome N	
Torsion dystonia N	Spinal muscular atrophy – Kugelberg-Welander N, S	

N = Northern Sweden; S = southern Sweden.

Number of clinical samples in the seven genetic laboratories in Sweden, 1996

Genetic centre	Gothenburg	Linköping	Lund	Skövde	Stockholm	Umeå	Uppsala	Total
<i>Cytogenetic analyses</i>								
Amniocentesis	994	482	1,042	158	2,320	341	422	5,759
CVS	92	12	26	39	144	37	233	583
Total prenatal	1,086	494	1,068	197	2,464	378	655	6,342
Blood ^a	953	135	639	221	992	505	558	4,003
Bone marrow ^b	–	–	379	75	404	341	372	1,571
Solid tumours	–	–	176	23	16	–	6	221
<i>Molecular analyses</i>								
Total ^c	441	–	228	79	612	415	668	2,443
Prenatal	29	–	12	–	40	–	32	113

^a Constitutional analyses.

^b Leukaemia/lymphomas.

^c Representing 68 different conditions.

Patient organisations

No information is available.

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Switzerland

Departments, Centres and Institutions Involved in Genetic Services

No information is available.

Workloads

No information is available.

Patient Organisations

No information is available.

.....
Turkey

Departments, Centres and Institutions Involved in Genetic Services

Hacettepe University Faculty of Medicine
Department of Paediatrics
Division of Medical Genetics
TR-06100 Sıhhiye, Ankara
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Faculty of Medicine
Department of Medical Genetics-GENTAM
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Hacettepe University
Faculty of Medicine
Department of Medical Biology
TR-06100, Sıhhiye, Ankara
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Head of the Department of Medical Biology
Trabzon

GATA, Medical Genetics Department
TR-06010 Etlik, Ankara
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Akdeniz University
Faculty of Medicine
Head of the Department of Medical Biology
TR-07070 Antalya

Bilkent University
Department of Molecular Biology
Bilkent
Ankara
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Firat University
Faculty of Medicine
Head of the Department of Medical Biology
Elazig

Ankara University
Faculty of Medicine
Head of the Department of Medical Biology
TR-06100 Ankara
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19 Mayıs University
Faculty of Medicine
Head of the Department of Medical Biology
TR-55139 Samsun

Ege University
Faculty of Medicine
Department of Genetics and Peratology
TR-335100 Bomova, Izmir
Tel. +90 232 4214352, Fax +90 232 4633916

Cumhuriyet University
Faculty of Medicine
Head of the Department of Medical Biology
Sivas

Istanbul University
Cerrahpasa Medical School
Department of Medical Biological Science
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Dicie University
Faculty of Medicine
Head of the Department of Medical Biology
Diyarbakir

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Department of Medical Biology
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Istanbul University
Institute of Child Health
PRETAM Millet cad. 34390 çapa
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Faculty of Medicine
Head of the Department of Medical Biology
Istanbul
Tel. +90 212 5181617, Fax +90 212 5181615

9 Eylül University
Faculty of Medicine
Clinic Genetics Unit
Izmir
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Bogaziçi University
Department of Biology, Chairman
Istanbul

Gazi University
Faculty of Medicine
Department of Medical Biology
Ankara

Istanbul University
Istanbul Medical Faculty
Department of Internal Medicine
Istanbul

Çukurova University
Faculty of Medicine
Department of Biology
Adana

Selçuk University
Faculty of Medicine
Head of the Department of Medical Biology
Konya

Atatürk University
Faculty of Medicine
Head of the Department of Medical Biology
Erzurum

Workloads

Institution	Peripheral blood	Bone marrow	Amniocentesis	CVS	Cord
Akdeniz Univ.	513	52 (+40 solid tumours)	20		
AU. Obst.-gynecol.			34	13	18
AU Medical Biology	838	245	9		7
Ataturk Univ.	340				
Celal Bayar Univ.	20	1 (+5 effusions)			5
Cumhuriyet Univ.	190				
Cukurova Univ.	1,133	10			11
9 Eylul Univ.	334	82 (+27 solid tumours)	47	2	19
Ege Univ.	800		200	17	35
Erciyes Univ.	385		60		5
Firat Univ.	60				
GMMA	700		250		100
Gazi Univ.	250		100		10
Gaziantep Univ.	92	15			
Eskisehir Univ. (Gentam)	628	81 (+27 solid tumours)	362	54	46
Hacettepe Univ.	695	92	472		85
IU Cerrahpasa (Gentam)	480				
IU Cerrahpasa	241				
IU Capa (Pretam)	674		643	70	226
IU Capa Internal Medicine	589	143	13	4	
Karadeniz Univ.	360				
19 Mayıs Univ.	284				
Selcuk Univ.	550				
Sevgi Hospital ^a	162	1	49		1
Uludag Univ.	50	8			
Zekai Tahir Burak Hospital ^a	163		44		7

GMMA = Gulhane Military Medical Academy.

^a For the first four months of 1997.

Patient organisations

No information is available.

Ukraine

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Workloads

No information is available.

Patient Organisations

No information is available.

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United Kingdom

Departments, Centres and Institutions Involved in Genetic Services

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Workloads

Further information is available from the authors.

Patient Organisations

The Genetic Interest Group (GIG) will provide full details of member organisations:

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In addition 'Contact-a-family' has a special role in putting families with a specific condition in touch with other families who are involved.

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