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Genetic Services in Latvia

Country Background: Demography, Geography and Infrastructure

The Republic of Latvia lies in north-eastern Europe and is 64,600 km^2 in area. It is bordered by Estonia in the north, Lithuania in the south and south-west, on the east there is a frontier with the Russian Federation and to the south-east with Belarus. At the beginning of 1996 there were 2,496,981 inhabitants in Latvia. The last census before World War II listed Latvians as comprising 77% of the total population; in 1995 Latvians make up 56.6% of the population and Russians 30.33%. Other ethnic groups are Belorussians, Ukrainians, Poles, Lithuanians, Jews, Gypsies, Estonians and Germans. Latvia's laws guarantee equal rights for all ethnic groups, regardless of their nationality. Since independence in 1990, the Latvian economy has been changing from a socialist planned economy to a free market economy. Educational reform is currently in progress but full implementation will take many years and extensive financial assistance to complete. The main religions are Lutheran and Roman Catholic.

Health Service Setting

Health care in Latvia is financed from central government and local budgets. Expenditure on health care is approximately 4.3% of the central government general budget for 1995. The overall responsibility for health care lies with the Department of Health of the Ministry of Welfare. The health service system in Latvia is now changing from a centralised free-of-charge Soviet form to a health insurance system with patient freedom to consult any doctor, and health care as part of a free market economy. At the moment, the provision of health care institutions with modern technology, equipment and drugs is inadequate. A health insurance scheme aimed at the whole population is currently being introduced.

Since 1995, state and local health care facilities have been partly paid for by the patients themselves. Most Latvians have a very low income, and the quality of human life has deteriorated, especially for the elderly. Social deprivation is one of the reasons why the number of patient visits to doctors has decreased and many cases of serious illness have been diagnosed late.

History of Medical Genetics

Medical genetics care has existed in Latvia since 1971, when some methods of genetic investigation (X chromatin and karyotype analysis) and genetic counselling were introduced in two centres: the Riga Medical Institute and the Marriage and Family Consultation Centre.

Dimension 1: Availability

At the moment genetics is recognised as an additional (non-basic) medical speciality.

In the whole of the country, 15 individuals have received genetic training (table 1), including 5 genetic

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Table 1. Medical genetics staff engaged in genetic service provision in Latvia

Number of centres	Population served	Genetically trained physicians	Genetic physicians in training	Cyto-geneticists	Molecular geneticists	Genetic nurses/ counsellors
1	2,496,981	7	–	7	4[a]	–

[a] Researchers are partly involved in genetic service provision.

counsellors, 3 paediatricians, 2 gynaecologists and 3 others. Of these, only 7 genetic counsellors and 2 cytogeneticists are directly involved in providing genetic services, and only 5 (3 genetic counsellors and 2 cytogeneticists) of those directly involved in providing genetic services work full-time.

The 7 cytogeneticists include 3 physicians (2 directly involved full-time) and 4 biologists directly involved full-time. Four full-time non-medically qualified biochemists contribute to genetic services.

There is only one medical genetics centre in Latvia – the Latvian State Medical Genetics Centre (established in 1986) – which is located in but financially independent from the State Children's Clinical Hospital 'Gailezers' in Riga. The clinical department of the Genetics Centre uses beds in two age-dependent wards of the hospital. The Genetics Centre, which provides genetic counselling, laboratory investigations, training and research, has five departments: (1) biochemical laboratory (prenatal and postnatal tests, neonatal screening and chromatography of amino acids); (2) cytogenetics laboratory (prenatal and postnatal examinations); (3) department of prenatal diagnosis (ultrasonography, chorionic villus biopsy (CVS), amniocentesis, fetal blood sampling); (4) Latvian State Register of birth defects which reports regularly on registered congenital malformations (all cases of diagnosed genetic disorders are also registered), and (5) clinical department (genetic counselling, in-patient care, PKU treatment and follow-up).

There are four molecular genetics laboratories connected with medical genetic care although there are no purely molecular genetic laboratories in Latvia. Until 1997, there was no molecular laboratory in the State Medical Genetics Centre. Three of these laboratories are in academic institutions (two in Latvia University and one in the Medical Academy of Latvia), which together analyse over 470 samples per year. Most involve leukaemia (mainly CML) and DNA analysis of HLA polymorphism in diabetes. Molecular diagnosis of cystic fibrosis (CF) and PKU has just started as a pilot study and no prenatal analyses have been performed so far.

There are three medical cytogenetics laboratories in Latvia (one of them in the State Medical Genetics Centre). The number of samples per year is about 800: 740 blood (postnatal) and 60 amnio/CVS. Cytogenetic examination of fetal blood has just started. No FISH analyses have been used to date. There is no central cytogenetic registry.

There is one biochemical genetics laboratory (in the State Medical Genetics Centre). The number of samples per year is 200 (chromatography of amino acids; data for 1994). In 1995, large-scale investigation of affected newborns and children for inherited amino acid disorders (HPLC amino acid analysis) began. All the biochemical analyses performed so far have been postnatal.

There are two immunogenetics laboratories related to medical genetics performing analyses of erythrocyte antigens, blood antibodies and HLA typing. A wide range of patients are investigated including those with recurrent abortions, infertility, disorders of the immune system, congenital abnormalities and Rh incompatibility. The number of patients per year is approximately 10,000 and the number of samples per year is approximately 70,000, not including blood banks.

Free (self-determined) abortion up to the end of the 12th week of pregnancy has been legal in Latvia since 1975. After the 12th week, a special committee of three physicians has to grant permission on medical grounds, which include prenatal diagnosis of genetic or congenital disorders. In practice, 24 weeks is a time limit which is not exceeded. The Department of Health of the Ministry of Welfare has issued written recommendations for indications for prenatal diagnosis.

Ultrasonography as a method of prenatal diagnosis was introduced in 1983. About 88% of women now have an ultrasound investigation during pregnancy. Ultrasonogra-

phy is used in weeks 20–22 as a screening method and later depending on the indications. Amniocentesis was introduced in 1986 and CVS in 1987. In 1995, the number of prenatal cytogenetic analyses was only 50 because of poor availability of laboratory reagents and equipment as well as poor public awareness. The invasive method selected depends mainly on the decision of the Prenatal Board consisting of two geneticists and one gynaecologist.

Mass screening of newborns for PKU was started in Riga in 1985, and in the whole of Latvia in 1987. Mass newborn screening for hypothyroidism started in 1995. The number of newborns screened for PKU is approximately 24,000 per year and for hypothyroidism, 12,000. All PKU children as well as children with hypothyroidism identified by screening are treated at the State Medical Genetics Centre. Children with CF are treated in the State Children Clinical Hospital in Riga; there is no screening for CF. Maternal serum AFP screening for all pregnant women to identify high risk of both neural tube defects and Down syndrome was available in 1991–1992, but is now restricted to women who are prepared to pay (about 2,000 analyses per year).

There is no testing for cancer susceptibility genes in Latvia.

Dimension 2: Access

Most patients with genetic problems gain access to genetic services via paediatricians, internists, obstetricians or general practitioners. In some cases patients or their relatives visit geneticists directly without referral. Most institutions involved in genetic service provision (the Genetics Centre and laboratories in the Latvian University and the Medical Academy of Latvia) are funded from the general state budget. Only an immunogenetics and one cytogenetics laboratory are private.

In principle, all genetic services and testing are free of charge for patients and families (except for maternal serum AFP screening). Generally, all consumers have access to the comprehensive list of genetic services regardless of age, income (with the exception of maternal AFP screening), ethnicity, health status or long-term need. However, the following impede access to genetic services: (1) administrators of welfare who hold the budgets and who are poorly informed about genetics; (2) most physicians who have little knowledge of genetics; (3) poor cooperation between geneticists and physicians; (4) the pattern of morbidity with a high percentage of e.g. infectious diseases, cardiovascular disorders and trauma; (5) adverse economic and social situation, and (6) low educational level of the population concerning genetics and poor public awareness of genetic services.

Dimension 3: Life Sustaining

The infant mortality rate in 1992 was 17.4 per thousand newborns compared with 15.9 in 1993, 15.5 in 1994 and 18.8 in 1995. Life expectancy (years) for males was 62, 61 and 60 and for females 74, 73 and 73 in 1993, 1994 and 1995, respectively. In 1994, the fertility rate was 1.39 per woman and the mean maternal age was 25.5 years. The percentage of women giving birth aged 35 years or more in 1994 was 6.18. The percentage of women giving birth aged 40 years or more in 1994 was 1.5.

Dimension 4: State of the Art

The Medical Academy of Latvia is the only higher educational institution where students and post-graduates for all medical specialities, dentists and pharmacists are educated. Few medical genetics topics were included in the students' curriculum until 1995 when a medical genetics course of 38 lecture hours and 38 laboratory hours was established in the Department of Medical Biology and Genetics. However the 15 geneticists in the Genetics Centre in Riga are not directly involved in the teaching of genetics to medical students.

Teaching of medical genetics in the Medical Academy to postgraduates includes short courses (5–15 h). Similar courses (approximately 15 h) in clinical genetics are organised annually by the Society of Latvian Physicians and are attended by paediatricians and obstetricians/gynaecologists. Some medical genetics topics are included in the educational programme of nurses.

As yet there are no published recommendations for training clinical or laboratory geneticists. Training in genetics for physicians to qualify as clinical or laboratory geneticists and for non-physicians to qualify as laboratory geneticists is carried out mainly by the specialists of the Latvian State Medical Genetics Centre. There are no accredited training programmes. The training is in the workplace and relies on the achievement of competencies. Clinical geneticists require the ability to diagnose genetic disorders, provide genetic counselling for patients and relatives and be familiar with the clinical aspects of cytogenetics and biochemical genetics. Until 1991, short-term

(1-month) training courses for Latvian geneticists were available in the Genetics Centres of Russia. In recent years, Latvian geneticists have increasingly visited west European and Scandinavian genetic centres.

Medical genetics laboratories have poor equipment and insufficient reagents and this limits the success of genetic services.

All advances in contemporary genetics may be introduced into health care only by physicians. As genetic disorders affect all ages and all body systems, an appropriate knowledge of genetics is of great importance for physicians in all specialties.

Different education systems exist in European countries and no one system can be recommended as the best. It must be emphasised that curricula for all medical specialties must include a wide range of medical genetic aspects with some elements of clinical genetics. More widely, the questions of clinical genetics should be included in the curricula for postgraduates, reflecting the specificity of the particular specialty.

Dimension 5: Non-Harmful

All specialists directly involved in providing genetic services have to be certified as medical geneticists. To obtain the certificate, the applicant must pass an examination in medical genetics which includes questions covering all branches of the discipline.

At the moment there are no laws in Latvia regulating medical genetics. Some instructions have been issued by the Department of Health of the Ministry of Welfare concerning medical genetic services. These include obligatory newborn screening, ultrasonography screening for fetal pathology and the registration of birth defects.

All health care professionals, including medical geneticists, are supervised by the Department of Health of the Ministry of Welfare and can be subject to sanctions for poor practices. To date there has been no quality assessment of genetic counselling, cytogenetics or biochemical and molecular laboratories. The only exception is the external control programme for newborn screening and the quality assurance programme for metabolic disorders introduced in 1995.

Primary (non-specialised) counselling is done by physicians in different departments, mostly paediatrics and gynaecology. Counselling advice given by telephone by geneticists to colleagues is well developed. In most cases, genetic counselling is non-directive, with the exception of serious fetal pathology when abortion is recommended.

In 1994, a Central Ethical Council was established at the Department of Health. This deals with a wide range of problems including patients' complaints, clinical approval of drugs, tissue transplantation, new reproductive technologies and experiments on animals. Questions of medical/clinical genetics have not been discussed so far.

Dimension 6: Effectiveness

It is practically impossible to estimate the effectiveness of genetic services in Latvia at present because of difficulties during a period of rapid change in the economy, health care organisation and education.

Dimension 7: Consumer Satisfaction

There are no investigations on the social impact of genetic services. There are a few patient and parent organisations including the National Society for PKU, for CF and for Down syndrome. These organisations do not have any influence over the decision-making process for genetic services.

Publications Related to Genetic Services

1 Statistics in Brief. Central Statistical Bureau of Latvia, 1996.
2 Vinkelis: Zinojums par stavokli veselibas aprupe Latvija. Latvijas Arsts, 1996.g., No 1.
3 Purina, Lugovska R, Sokolova L, Martinsons A, Bars J, Dislere A, Vevere P: Medical genetical service in Latvia: Developmental trends. Proc Latv Acad Sci 1995; No 5/6.

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