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Genetic Services in Serbia

Country Background: Demography, Geography and Infrastructure

Yugoslavia consists of Serbia and Montenegro. It is situated in the central part of the Balkans and has a population of approximately 10,500,000: Serbia 9,800,000 and Montenegro 620,000. Serbia is 88,361 km^2 in size. The population density is 102 people/km^2. It is a republic with a parliamentary democracy. The literacy rate is 90%. The religions of the country are Orthodox Christians (Serbs, Montenegrins, Yugoslavs) then Muslims (Albanians, Slav Muslims) and Roman Catholics (Hungarians, Slovaks, Croats). The ethnic composition of the country is as follows: 64% Serbs, 15% Albanians, 5% Montenegrins, 3% Hungarians, 3% Yugoslavs, 3% Slav Muslims and smaller groups of Slovaks, Gypsies, Romanians, Ruthenians and Croats. Due to the recent war in the area and sanctions against Yugoslavia, the infrastructure was badly damaged and the economy collapsed. There are around 650,000 refugees from Bosnia and Croatia living in Serbia.

At the beginning of the war in Yugoslavia, the first financial cuts were in science, and genetics was included in this field. When the sanctions were announced, several contracts with foreign partners in molecular genetics and in cancer genetics were cancelled. There was no possibility of importing e.g. foreign chemicals, media or devices. The genetic service in Novi Sad was reduced to cytogenetic analyses of peripheral blood karyotypes, prenatal diagnoses and genetic counselling services. Two screening programmes (for PKU and hypothyroidism) ceased because of lack of money. Regional EUROCAT money was not recognised. In Belgrade, two molecular genetic laboratories which had begun work on cystic fibrosis (CF) and Duchenne muscular dystrophy (DMD) stopped their projects. Two cytogenetic laboratories were closed for 3 years. Others continued the work with difficulties. Priority was given to prenatal diagnosis and cytogenetics.

Health Service Setting

The health care system is organised as a social security system funded by the state budget. The responsibility for overall organisation of health care lies with the Ministry of Health. The health insurance system covers 100% of the population. Health care is free for patients and includes medical care from the GP, specialist care when needed and hospital in-patient services. Basic genetic services are also included free of charge.

The country is divided into regions with general hospitals in all bigger towns and departments with GPs in small towns and villages. Primary health care in Yugoslavia is based on GPs working in health service centres organised throughout the country. GPs in each health service centre are responsible for health care for approximately 5,600 individuals in the area. Beside GPs, there are a few specialists (usually paediatricians, ORL, gynaecologists) and nurses working in bigger health service centres. Except in emergency cases, all patients first contact GPs in their local health service where they are registered. When nec-

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essary, GPs refer patients to a specialist hospital. GPs are usually generalists. There is a 2-year training and a final examination for GPs who wish to become specialists of general medicine. About 30% of GPs are specialists of general medicine.

There are 20 doctors and 58 hospital beds per 10,000 inhabitants. In 1994, there were 20,690 physicians in Yugoslavia, about 1 per 500 inhabitants. There are 4,400 GPs (21%), about 14,000 specialists (67%) and 2,400 on specialisation.

The co-ordination between genetic service and primary health care is through the GP who gives primary information and sends patients with a suspected genetic disorder to a hospital with a genetic centre or consultant. In bigger medical centres, specialists (e.g. gynaecologists, paediatricians, endocrinologists) consult genetic specialists for disorders connected with genetics. Responsibility for organising genetic services lies on general hospital management and the Ministry of Health as the founder of medical services.

History of Medical Genetics

Clinical genetic research began in 1968 at the Hospital for Mental Health in Belgrade, where karyotypes were performed on patients with mental retardation. From that year, a registry for Down syndrome came into existence. In 1970, cytogenetic laboratories were established at the Paediatric Clinic and Institute of Oncology in Belgrade and a cytogenetic laboratory organised at the Paediatric Clinic in Novi Sad. The first prenatal diagnosis – amniocentesis – was performed in 1980 at the Institute for Mental Health in Belgrade.

Dimension 1: Availability

There are two regional clinical genetic centres in Serbia situated in hospital centres in the largest cities: Belgrade and Novi Sad. Several genetic laboratories are present in smaller towns (table 1). In principle, genetic services are free of charge for the patients and families. Some of the more advanced medical and genetic analyses are not within primary care and patients pay percentages of the cost, depending on the type of disorder and analysis. (Private medical practice began 5 years ago and has developed since then. Very few genetic laboratories are included in the private medical service). Abortion is allowed up to the 12th week of gestation. After the 12th week, a medical committee within a hospital considers each individual case on social and medical grounds.

Genetic services in Serbia are linked with general health services in regional hospitals or in different departments or clinics (e.g. paediatric, reproduction and fertility clinics, mental health). There are several genetic laboratories in smaller centres.

The centre in Novi Sad was founded for the population of the northern part of Serbia with approximately 2 million inhabitants. There are 12 specialists in the paediatric clinic: 6 are medical doctors (2 of them finishing specialisation) and the remaining are biologists and coworkers. There are also two small genetic laboratories in the region working on cytogenetics and population studies. There are 15 genetic counselling services in local health service centres/hospitals in this region where trained paediatricians are performing genetic counselling. One centre in Novi Sad sees about 1,800 patients per year in the genetic counselling service and this number increases every year. Recently, information about genetic service facilities has been offered through e.g. the media, short publications, hospital newsletters and TV reports. Prenatal cytogenetic diagnoses have been performed since 1985 in Novi Sad. From 1990 to 1996, there were 2,237 amniocenteses, 437 cordocenteses and 147 chorionic villus samples (CVS). There is a 'hot teratogene line' (this is an open telephone service for all kinds of inquiries about harmful effects of any kind on pregnancy) in the Novi Sad genetic counselling service which is working non-stop with a database covering more than 1,500 teratogenic agents. About 1,100 cytogenetic analyses per year from peripheral blood are performed. A cytogenetic registry has existed since 1970 and reports have been published since 1990. For biochemical geneticists there is co-operation with a laboratory in Pecuj and Szeged in Hungary. Genetic specialists are always present when patients receive their test results. Laboratory reports are signed by the head of the laboratory and the patient's doctor. There are no molecular genetic laboratories in this region. Genetic screening was performed before the war (until 1991). In 11,000 live births there was 1 PKU, in 3,500 live births 1 congenital hypothyroidism and 1 CF. The Down syndrome rate is 1 per 780 live births.

Neural tube defect (NTD) is still followed up in cases where the families are at risk. Specialists competent in genetics are included in the specialist teams for certain disorders.

In Belgrade there are about five genetic services organised as hospital units in paediatric hospitals, clinical centres and one general hospital. The Belgrade genetic

Table 1. Number of medical genetic staff engaged in genetic service provision in Serbia and Montenegro

Number of centres	Population served	Genetically trained physicians	Genetic physicians in training	Cyto-geneticists	Molecular geneticists	Genetic nurses/ counsellors
5	10,500,000	11	11	25	10	6

service is comprised of 7 medical doctors trained in medical genetics and 21 biologists working in clinical genetics. The following genetic services can be obtained in Belgrade centres: genetic counselling, prenatal diagnoses, blood cytogenetic techniques including FISH, some biochemical genetic analyses, and some molecular genetic analyses.

In paediatric hospitals and some gynaecological departments, the main field of work is in genetic counselling and prenatal diagnosis (amniocenteses, CVS, cordocenteses). Prenatal diagnosis is increasingly accepted. The indication is maternal age of 35 years and over for the general population. About 35–40% of pregnant women over 35 have some sort of prenatal diagnosis. The northern part of Serbia and the Belgrade area have the highest uptake. About 80% of women have an ultrasound investigation during pregnancy, which is widely accepted. A biochemical laboratory is doing AFP. All genetic counselling services in Belgrade have about 2,500 patients per year. Over 1,800 prenatal diagnoses are made per year in Belgrade centres.

Newborn screening for PKU and hypothyroidism has been established since 1976 and since 1994 for neuroblastoma.

Prenatal and postnatal molecular genetic analyses of CF and DMD have been carried out since the beginning of 1996. A register for CF families has been established since 1987.

In Belgrade genetic centres, all cytogenetic analyses from blood (including FISH) are performed. Meiotic analyses are done in infertile males. Cancer genetic studies include about 600 bone marrow analyses per year and about 100 solid tumour investigations by direct cytogenetic and molecular genetic techniques per year. There is a follow-up of families with fragile X chromosome. The national congenital malformation registry is in the Novi Sad genetic centre. Since 1990 there have been 15,025 children registered and 2.68% have congenital malformations. EUROCAT is also used, although it is still not recognised as a regional centre due to the sanctions on Yugoslavia in recent years.

Dimension 2: Access

All consumers have access to genetic services in Serbia regardless of age, ethnic group, income level or other differences or needs. In actual fact there is a difference among groups of people depending on where they live. Consumers in towns are much better informed about genetic service facilities than people from villages, especially in the southern part of Serbia and Kosovo. In larger centres, individuals eligible for genetic tests are informed by their GPs or other specialists and receive genetic services. In some rural and remote areas of the country and in Kosovo, with an ethnic group of low educational and income level, people are not well informed and accessibility to genetic services decreases. Generally, public awareness of genetic service possibilities is low. Other important factors which impede access to genetic services are the lack of money for funding new genetic laboratories in central and southern Serbian hospitals, lack of genetic specialists, and poor organisation and co-operation between GPs and geneticists. Administrators are poorly informed about genetics and the reimbursement of genetic work is low.

Health insurance covers cytogenetic analyses in all indicated areas, fetal karyotyping and postnatal karyotyping. Molecular genetic work is only partially covered by funds from the Ministry of Science and Technology. This is considered scientific research and some financial support comes from pharmaceutical companies, although not a very significant amount. Molecular genetic use is limited to some cheaper methods and techniques.

Dimension 3: Life Sustaining

The annual birth rate is continually decreasing and is 13.5 newborns per 1,000 (1994). Mean maternal age is 23. The infant mortality rate has increased since the beginning of the war. In 1991 it was 20 per 1,000 livebirths (Vojvodina 12.3, Kosovo 33.7). In 1994, the infant mortality rate in Yugoslavia was 21.9 per 1,000 livebirths (Vojvodina 15.2, Kosovo 33.3). 6.2% of live births are to women aged 35 and over. Life expectancy for men is 68.5 years and for women is 73.5 years.

Dimension 4: State of the Art

Geneticists working in clinical laboratories are biologists and medical doctors by basic education. In the course of their studies they receive a general knowledge in genetics and some practical work in cytogenetics. Undergraduate medical studies include biology and human genetics in the 1st year with 60 h of theoretical and 45 h of practical work. After that they finish a 2-year postgraduate course in human genetics to become a Master of Science. This programme consists of theoretical and practical education in all fields of human genetics. The postgraduate 2-year training course is mostly attended by medical doctors and a few molecular biologists. At the end of the course there are exams and a written thesis to be completed to obtain the certified degree 'Master of Medical Genetics'. This diploma qualifies them to work as specialists in medical genetics in their own field of medicine. In Novi Sad there is a 1-year course in clinical genetics for paediatricians, gynaecologists, physiologists and some other medical specialists. There is an exam at the end of the course. Organised continuing professional education in the subject is provided. All courses are organised at medical faculties. Most of the new techniques are only demonstrated to postgraduate students. There are few molecular genetic services in Belgrade (PSR) which are not used in the educational process.

At the medical faculty in Belgrade, a 2-year speciality course in medical genetics has started and it will be legally recognised. The programme of specialisation is similar to the postgraduate course with some further training in different fields of clinical genetics.

There is no officially organised inspection of training centres and no explicit arrangements for linking clinical and molecular genetics and cytogenetics in tertiary centres. A small proportion, less than 10%, of geneticists operate in isolation. Collaboration amongst genetic laboratories and geneticists mostly depends upon personal connections. Laboratory equipment is a limiting factor for applying more advanced techniques, hence cytogenetics is used in most centres.

The register for Down syndrome was founded in 1965 and there are 1,500 children registered to date. The incidence is about 1 per 780 live births.

Dimension 5: Non-Harmful

All medical and dental professionals are subject to quality assessment by a health committee organised on different levels. In genetic practice there is no such organisation. No specific legislation exists to protect patients using genetic services.

There are regular meetings of the Society of Human Genetics which include clinical geneticists, molecular geneticists and cytogeneticists. An association for biochemical geneticists or coworkers does not exist. There are no quality assessment schemes for genetic services. Protocols for patients' files and registers are confidential and accessible only to laboratory geneticists and patients' doctors.

Dimension 6: Effectiveness

The high number of prenatal diagnoses done every year in Belgrade and Novi Sad show they are widely accepted as a preventive method for having healthy offspring. Consumers are provided with information and options at the appropriate stage.

It is estimated that about 30% of women over 35 years of age receive fetal karyotyping. In the north this percentage is higher, whilst in the south of the country it is very small. About 2–3% of pregnancies are terminated because of chromosomal abnormalities. However, a decrease in Down syndrome birth incidence has not been observed in Serbia. Anomalies like NTD, various anaemias or some congenital malformations, when detected, are always discussed with parents at the appropriate time. This relates mostly to individuals in bigger centres. No prospective studies of individuals who are genetically susceptible have been undertaken.

Dimension 7: Consumer Satisfaction

There are no studies of consumer satisfaction or views of procedures. A patients' organisation does not exist. Very few public forums discuss medical genetic problems or ethical questions arising from new genetic methods.

Publications Related to Genetic Services

1 Yearly Report from the National Institute for Health Care.
2 Popic-Paljic F, Krstic A: Geneticko Savetovanje (genetic counselling). University in Novi Sad, 1995.

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