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Genetic Services in Romania

Country Background: Demography, Geography and Infrastructure

Romania is a presidential republic with a population of 22,789,000 which has, however, been falling during the last decade. The national language is Romanian. The special feature relevant to genetics services is the ethnic composition of the country: 89.4% of the total population are Romanians, 7.1% are Hungarians, 1.8% are Gypsies, 0.5% are Germans and there are small groups of Ukrainians, Armenians, Turks, Tatars, Bulgarians and Serbs (together 3.3%).

Health Service Setting and Primary Care

The health care system has remained almost unchanged from the Communist era. Medical care remains free of charge and there have been no developments in health insurance services in the last 7 years. Expenditure on health care was 2.7% of GDP in 1995 and 1996. This lack of policy direction and low prospects for medical and social improvements lead to a difficult situation; generally, hospitals lack proper technical equipment, medicines are extremely expensive, and most significantly, approximately 5-10% of graduated medical students (usually the high achievers) leave Romania every year for western Europe and the USA.

History of Medical Genetics

It is difficult for foreigners to comprehend the unfortunate history of Romanian medical genetics. The Soviet 'iron curtain' separated Romanian physicians from their Western colleagues and the only way to remain in contact with medical developments in the west was to emigrate. Very few physicians were able to attend international congresses and, apart from a few gifts from foreign colleagues, publications were not allowed into the country. From 1959 until the end of Soviet rule and the Lysenko era, genetics was out of favour with the Communist Party. During this period, medical genetics was limited to cytogenetics, syndromology (more specifically case descriptions) and the epidemiology of congenital malformations. Paradoxically, this situation has altered little since 1990 because health ministries and other medical authorities cannot grasp that molecular genetics is crucial to the future of medicine. The majority of physicians who went abroad for training never returned because molecular services were not available in Romania and no programmes for purchasing them were developed by the authorities. No encouragement was given to young enthusiastic scientists and many molecular biologists with MD degrees are still working abroad in the hope that things may improve in Romania. Against these odds, some medical geneticists are able to do serious scientific work and publish in international journals. The election of a new government in November 1996 has raised expectations that medical genetic developments may come soon.

¹ The editors deeply regret that Professor Maximilian died on April 11 1997.

Dimension 1: Availability

Medical genetics was only recognised as a medical speciality in April 1997 and no training system is available. Consequently, there are no real medical geneticists and no genetic nurses in Romania. All our medical geneticists, with the exception of two or three physicians, are self-educated people.

There are many scientific institutes with interests in genetic disorders, such as the Haematological Institutes in Bucharest, Cluj and Timisoara, the Oncologic Institutes in Bucharest and Cluj, the Endocrinology Institute in Bucharest and the Institute for Mother and Child in Bucharest. There are only three genetic counselling clinics although university clinics and non-university children's hospitals do offer such counselling.

A great deal of research is focused on medical genetics, but no scientific institution has a well-defined policy, with the exception of the 'Victor Babes Institute of Human Genetics and Pathology' based in Bucharest. This is a large laboratory of human genetics dedicated to cytogenetic diagnosis (especially of human malignancies) and research.

There is no regional organisation of genetic services in Romania and no national network of genetic centres. Integrated clinical and laboratory services are recognised as desirable but proposals by foreign scientists and organisations to create unitary centres in Romania were consistently refused by the former authorities.

Data on genetic families are incomplete as a result of poorly organised screening programmes. National registers for a few diseases, e.g. diabetes mellitus, sickle cell disease, β -thalassaemia and congenital malformations, have been established. Regional registers have been developed for hereditary colorectal cancer, but not for other common cancers, such as gastric and pulmonary cancers. Patients and their relatives involved in screening programmes are not entitled to molecular genetic tests because of the extremely poor financial position of medical genetic centres which do not have molecular genetics facilities. However, thanks to the kindness of foreign medical professionals, arrangements have been made for scientists to perform molecular studies in western countries. At present, there are no prenatal or postnatal screening programmes in Romania; prenatal biochemical screening, prenatal screening on maternal age, new born screening and population screening for carriers of recessive disorders do not exist.

It is difficult to be precise about what is and what is not available in Romania because even the cytogenetic diag-

nosis of common genetic disorders is currently not available in all major centres. No FISH or molecular tests are available anywhere. Only 15 laboratories can perform cytogenetics (G-banding of variable quality), mainly from the peripheral blood lymphocytes, bone marrow or lymph node cells.

Dimension 2: Access

There is no medical discrimination on the grounds of age, gender, ethnicity or educational level. There is no 'budget' for genetic services and such medical services are not widely available in Romania (see Dimension 1). Full reimbursement for genetic services does not exist. The government contributes to the salary of geneticists (about US\$ 100 per month) and each laboratory is financed by the medical unit to which it belongs. Although genetic services are free of charge to everyone and there are no socio-economic, religious or legal barriers to abortion, access by the population is very limited. There are three reasons for this: (1) poor genetic knowledge of non-geneticist doctors (e.g. GPs, for whom no teaching of medical genetics is organised); (2) poor supply of materials in the few existing genetics centres, and (3) the small number of genetic 'specialists', with funding difficulties for new posts for physicians and specialist laboratory geneticists.

An attempt to develop private genetic laboratories to expand services was not pursued by the medical authorities.

Dimension 3: Life Sustaining

The status of health is very poor and Romania is almost last in Europe for infant mortality and life expectancy (particularly for men). Infant mortality was 21.2 per 1,000 (1995) and 22.1 per 1,000 in the first 9 months of 1996. Male life expectancy was 65.88 years, and female life expectancy 73.32 years. Cancer genetics services are limited to cytogenetic studies. Although a few regional registers have been set up in some centres there is no linking net.

Dimension 4: State of the Art

There are no training programmes for medical genetics. In 1995, a 1-year course was proposed but never put into practice.

There are no published recommendations for teaching genetics to medical students, training medical geneticists, training laboratory geneticists, training genetic nurses/associates or for minimum laboratory equipment.

Dimension 5: Non-Harmful

No information is available on inspection/approval of training centres or accreditation/certification of specialists. There are no published audit reports of genetic services. There are no published reports on confidentiality, ethics or screening. There is a Medical Council with disciplinary authority and a National Ethics Council, although these are not often utilised.

Dimension 6: Effectiveness

There are no regular public debates on genetic issues. There are no published reports on outcomes.

Dimension 7: Consumer Satisfaction

There are no published reports on consumer satisfaction. There are no active and influential patient organisations.

Publications Related to Genetic Services

No information available.

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'As a representative of the Romanian Society for Medical Genetics I confirm the accuracy of the data enclosed in chapter on Genetic Services in Romania, written by Dr. D. Stefanescu.'