

to prevent new diseases, which have been identified in the last few years, and evaluated highly the seven-year experience of Bulgaria in this field.

In 2000–2001 the genetic prophylactic program targeted to Roma was expanded to cover Roma groups from different areas – Rousse, Lom, Sliven, Senovo, Kyustendil, Koynare, Gradi-na, Sadovetz, Byala Cherkva, Yavoretz, Dushevo, Shumata, Slunchevo, Katunitza, Kaloyanovo and elsewhere. The people involved in the program were screened for several hereditary diseases including hereditary motor and sensory neuropathy, Lom type, muscular dystrophy gamma-sarcoglycanopathia, congenital myasthenic syndrome, galactokinetic deficit, and others. The research revealed that in some areas the frequency of inheritance is very high. In Lom, for example, the frequency of inheritance for hereditary motor and sensory neuropathy, Lom type, reaches 20%. In Senovo the inheritance of muscular dystrophy gamma-sarcoglycanopathia also runs around 20%. This means that the risk of new cases in these and other areas is high, which increases the need to extend genetic prophylaxis of the risk Roma communities.

The prophylactic program also included some activities aimed at improving health knowledge:

1. Informing local medical staff

The experience of the research team shows that general practitioners and local medical experts (neurologists, therapists, pediatricians, gynecologists and obstetricians) are not well informed of the specific health problems confronting Roma and do not take advantage of the existing prophylactic programs. One of the main tasks of the research team was to inform local medical staff and to involve local physicians in the prophylactic activities. The team visited and talked to a number of specialists in the regional healthcare establishments, which cooperated in realizing the prophylactic program.

2. Informing the members of the risk groups

During our visits in the Roma neighborhoods we tried to increase the awareness of young people from the risk groups by explaining in detail *what are the hereditary diseases, why do they occur, how are they inherited, how are genetic tests done, what can be done after that, what choice do couples who carry defective genes have, how are pregnant women tested*. Health information was provided door to door in order to cover all members of the target group. The research team visited houses across the Roma neighborhoods and was often assisted by Roma activists and medical staff.

3. Informing local Roma associations and foundation and conducting joint prophylactic activities. Training and encouraging Roma medical staff – doctors, doctor's assistants, nurses, obstetricians and students – to work with families in which the risk of hereditary diseases is high.

A large-scale prophylactic program was carried out in all Roma neighborhoods of Lom (Mladenovo, Humata, Stadion) in cooperation with activists from the Roma – Lom Foundation. A prophylactic and health education program was also carried out in the Iztok District in Kyustendil together with the nurse Vassilka Alexandrova from the Nevo Drom Association. Families identified by the general practitioners and the Roma nurses in the neighborhood were tested clinically and were consulted in their homes. The team cooperated with Dr. Manolov and Dr. Panayotov from the Roma Health Foundation to conduct a health education and screening program among young Roma in reproductive age from the Nadezhda District in Sliven. Chronically ill and disabled patients from the neighborhood were also visited and consulted. Together with the Integro Association and the local Roma medical staff (the doctor's assistant Lilia Makaveeva) the team conducted a thorough research of the health status of Roma in Senovo, as well as clinical tests and home visits of patients in Senovo, Vetovo, Ravno, Rakovski, Ostrovo,