

SOUTH-EASTERN EUROPE REGIONAL CONSULTATION

**“Children with Genetic Diseases: Policy and Practice in countries of
South Eastern Europe”**

21-22 February 2008, Tirana / Albania

**CONCLUSIONS AND
RECOMMENDATIONS OF THE
REGIONAL CONSULTATION**

1. Background of the initiative

The Children's Human Rights Centre of Albania / Defence for Children International – Albania (CRCA / DCI Albania), is one of the major civil society organisations in Albania and the region of South Eastern Europe working to improve the situation of children's and youth rights through lobby and advocacy, capacity building, policy and legislation formulation.

In January 2008 CRCA / DCI Albania together with Open Society Foundation in Albania (Soros Foundation) initiated the joint-initiative "ALEX and Vladi" that aims to improve the right to life of children with genetic diseases in South Eastern Europe, respectively in Albania, Bulgaria, Croatia, Kosovo, Slovenia and Serbia. Partners of the initiative include Child Rights Center Belgrade, DEBRA Croatia, SEECRAN, CRCA Kosovo etc.

The initiative "**ALEX AND VLADI**" aims to debate and suggest strategies for Public Health Services in dealing with children with genetic diseases under the framework of UN Convention on the Rights of the Child and the right of the child to life in countries of South-East Europe. The initiative would review and exchange regional country experiences on public health policies in guarantying the respect of the rights of the child.

Part of the initiative was the organisation of the **Regional Consultation "Children with Genetic Diseases: Policy and Practice in countries of South Eastern Europe"**, that took place on 21-22 February 2007 in Tirana / Albania. Participants of the event were representatives of NGO's and national health institutions from Albania, Bulgaria, Croatia, Kosovo, Serbia and Slovenia. During the two-day event the participants debated and presented national experiences from their countries, while focusing on what should be done to guarantee the right to life of children with genetic diseases.

Below there is the list of conclusions and recommendations of the Regional Consultation.

2. Areas of concern – Conclusions

During the two days of work of the Regional Meeting, the country representatives, after took into consideration the existing practices, policies and legislations, presented the following conclusions:

- a) Available data collection, analysis and reporting does not always provide enough disaggregated information on gender / age / diagnosis / incidence of children with genetic diseases in countries of SEE.

- b) Children with genetic diseases are not recognised as a major public health issue by institutions and large public alike, thus often they lack appropriate and whenever best possible medical treatment.
- c) Children's rights are not fully respected or taken into consideration by policy makers and decision-makers in SEE countries;
- d) In SEE countries there is lack of information and education practices for parents, social and health workers, teachers on how to deal with children with genetic diseases;
- e) Albania and Kosovo do not carry genetic screening of the new born in order to provide children with a genetic diseases with appropriate medicines and supporting services from the moment of the acknowledgement of the diseases;
- f) Inadequate supportive treatment (medical / psycho-social / professional) for children with genetic diseases puts in danger the right to life of children.
- g) In several countries of SEE there is a lack of political will to recognize the issue of children with genetic diseases and to act in their support;
- h) Legislation in SEE countries has limited or lacks legal provisions to support children with genetic diseases in their right to health, education and social services;
- i) Best possible services, especially in the area of diagnosis (guidelines, protocols, equipment and human resources) are not available to children with genetic diseases living in SEE countries.
- j) Countries of SEE have limited financial resources. However in some cases this is not only a matter of available financial resources but the available funds are not appropriately managed or distributed;
- k) Civil society networking in many countries of SEE, especially among patients organisations is weak or fragmented. Lack of strong civil society networks often undermines the lobby and advocacy measures that shall be exercised to protect children's interest to the public institutions and private sector alike;

- l) Although there are few positive practices in terms of care and protection of children with genetic diseases in the SEE region they are not shared widely with governments and civil society;
- m) Media and public opinion is not aware of the issue of children with genetic diseases. Since information on children with genetic diseases is not widely available and accessible there are few sources of information that can inform the general public, institutions and media on the situation of the group.

3. Recommendations of the Regional Consultation

- a) Authorities shall improve data collection and analysis by requiring data to be disaggregated into gender, ethnicity, geographical area diagnostics and incidence. Funding shall be increased into analytical research of incidence of children with genetic diseases and how services are being provided;
- b) Develop new legislation and policies in the area of prevention and protection of children with genetic diseases (for example free of charge medicines, screening of new born child etc).
- c) Countries in SEE shall use participatory approach to include all the interested groups (professionals, politicians, parents, children, universities, researchers, private businesses) in the preparation of new policies and legislation for children with genetic diseases;
- d) Develop a Reference Center for Genetic Diseases for all Western Balkans based in one of the countries and with specialised centers for one or more genetic diseases in every country of SEE;
- e) Set up protocols and guidelines for prevention, early detection, proper diagnosis and treatment and rehabilitation (social inclusion);
- f) Albania and Kosovo shall prepare and enact new legislation on the national screening of the new born children in order to provide children with a genetic diseases with appropriate medicines and supporting services from the moment of the acknowledgement of the diseases;

- g) Civil society in every country, but also in the region, shall seek new ways to strengthen networking capacities in order to lobby and advocate on behalf of the children with genetic diseases and provide expertise to authorities and parents alike;
- h) Authorities shall recognise the issue of children with genetic diseases as one of the major public health issues that affect children in every country of SEE. Saying this the authorities shall undertake all the necessary steps to increase funding and public expenditure to best possible medicines and services for these children;
- i) New models of inclusion at schools, family and communities shall be supported by the Government and civil society aiming to increase the respect of children with genetic diseases rights and their social inclusion at every decision that is taken on their behalf;
- j) Civil society and media play an important role in informing public opinion on the situation of children with genetic diseases, their concerns and positive models of care and protection, while reducing stigma towards them. The establishment of information-share platforms on children with genetic diseases would help children, parents, teachers, public officials, media and experts to exchange information not only on best available practices, but also focus on the daily life and problems faced by children.