საქართველოს შრომის, ჯანმრთელობისა
და სოციალური დაცვის სამინისტრო
MINISTRY OF LABOUR, HEALTH AND SOCIAL
AFFAIRS OF GEORGIA

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№ 01/35362 **18 / June / 2018**

Mr. Christian Gruttke
Official in Charge
Embassy of the Federal Republic of Germany to the Georgia
20 Telavi Str. 0103 Tbilisi, Georgia

Subject: Reference to RK-10-516.80 E Mirage – Syndrome u.a.

Dear Mr. Gruttke,

Let me express the assurance of my highest respect and acknowledgments for continuous support, reliable partnership, and fruitful collaboration for over the years.

Herewith, let me kindly provide you with the requested information within the competence of the Ministry of Labour, Health and Social Affairs of Georgia:

Question A) Is treatment of children of four years and older suffering from Mirage syndrome (ataxia-pancyptopenia Syndrome) with a mutation in the SAMD9L-gene possible in Georgia?

Question B) If yes, what kind of treatment would be administered?

Mirage syndrome is a form of syndromic hypoplasia of adrenal glands that is characterized by myelodysplasia, infection, growth hysteria, hypoplasia of adrenal glands, imbalance of genital phenotypes, enteropathy. The outcome of this condition often is lethality in the first 10 years (mainly, due to the invasive infections).

Mirage syndrome is performed by heterozygote mutation of SAMD9 (610456) gene on the 7q21 chromosome.

This combined pathology has been separated as a syndrome in 2016 (Narumi et al.), therefore there is lack of information on the similar clinical case in our country, Thus there is no experience of managing this process (diagnosis and treatment).

Hereby in response to your questions a) and b) please be informed that in Georgia the treatment of the above mentioned syndrome is impossible because of lack of experience.

Question C) – Is treatment of children of four years and older suffering from acute myeloid leukemia (AML) possible in Georgia?
Question D) – If yes, what kind of threatment would be administered? Would it be possible, in particular, to receive treatment through chemotherapy or stem cell transplantation?

In Georgia the treatment of pediatric AML is performed on the basis of AML-BFM-2004 chemotherapy, with the support of all diagnostic procedures and multidisciplinary care approach. Stem cell transplantation is not possible in Georgia.

Question E) – Is treatment of children of four years and older suffering from myelodysplastic syndrome (MDS) with hypocellular and refractory cytopenia possible in Georgia?

Question F) – If yes, what kind of treatment would be administered? Would it be possible, in particular, to receive treatment through stem cell transplantation?

Treatment of MDS patient is limited in Georgia for all ages, because of the lack of SCT service in Georgia, which is main option of treatment of MDS, children treatment of MDS includes palliative procedures only: like blood component transfusion and antibiotics.

Question G) – Is it possible to treat children of four years and older in Georgia suffering from

a. Disorders of speech development

b. Hypertonia (ICD 10.90)

c. Infratentorial and subcerebellar arachnoid cyst (ICD G93.0) and

d. Hypoplasia in the corpus callosum (ICD Q04.0)?

Question H) If, yes, how would the conditions as stated in g) letters a to d be treted in Georgia?

Treatment and follow up of developmental problems as language development (a), hypertonia (b) that involve monitoring by psycho neurologists, occupational, behavioral and speech therapist is available in special early interventions center and follow up for this problems can be provided.

Follow up of patients with hypoplasia of corpus collusum (d) and arachnoid cyst (c) can be provided by neurologists.

Question I) – Are follow-up examinations possible and what kind of follow-up examinations would be possible for

a. Mirage syndrome (Ataxia-pancyptopenia Syndrome) with a mutation in the SAMD9L-gene

b. Acute myeloid leukemia(AML)

c. Myelodysplastic syndrome (MDS) with hypocellular and refractory cytopenia

d. Disorders of speech development

e. Hypertonia (ICD 10.90)

f. Infratentorial and subcerebellar arachnoid cyst (iCD G93.0) and

g. Hypoplasia in the corpus callosum (ICD Q04.0)?

a. As we have already noted the treatment of above mentioned diagnosis is not possible in Georgia, so no relevant examinations and follow-up can't be achieved.

b. Treatment of pediatric AML in Georgia is performed by all necessary procedures, (except stem cell transplantation).
c. Treatment measures for the myelodysplastic syndrome are limited in Georgia.
d. e. Monitoring of the problems such as: disorder of speech development, hypertonia can be provided;
f. g. Monitoring of patients with hypoplasia of corpus collusum and arachnoid cyst can be provided by neurologists.
j. Due to the fact that in Georgia "Mirage syndrome" has not yet been identified, it is not included in the list of the nosologies financed by the state program. Thus, the cost of treatment under the state program can not be reimbursed.

Treatment of acute myeloid leukemia (except for stem cell transplantation, which can not be carried out in Georgia) is fully covered (100%) within the "Children's oncohemological services" healthcare state program, but monitoring of patients with hypoplasia of corpus collusum and arachnoid cyst aren't covered by the healthcare state program.

Therefore in Georgia treatment for Mirage syndrome, stem cell transplantation in case of need of leukemia and treatment of MDS cannot be provided.

In case of any additional questions please do not hesitate to contact us.

Sincerely,

Head of HR Management and International Relations Department — Sofiko Belkania