



Embassy
of the Federal Republic of Germany
Tbilisi

Embassy of the Federal Republic of Germany, 20 Telavi Str., 0103 Tbilisi, Georgia

Ministry of Labour, Health and Social Affairs
of Georgia

Att.:
Ms. Sopo Belkania
Head of HR Management and
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Subject **International Cooperation concerning Health Care and Availability of Medical
Treatment in Georgia**

Your Ref. -

Encl. -

Our Ref. (please refer to in your answer) RK-10-516.80 E Mirage-Syndrom u.a.

Tbilisi, June 4, 2018

Dear Ms. Belkania,

Thanking you again for your kind offer for assistance on the occasion of the joint meeting between His Excellency the Minister of Labour, Health and Social Affairs, Mr. Sergeenko, you and the Embassy of the Federal Republic of Germany to Georgia on February 28, 2018, I herewith kindly request your assistance in obtaining information regarding the following medical questions:

1. Case summary

The patient in question is a four year old Georgian national currently residing in Germany and suffering from **Mirage syndrome (Ataxia-pancytopenia Syndrome) with a mutation in the SAMD9L-gene**. Additionally, he is suffering from a myelodysplastic syndrome (MDS), disorder of speech development, hypertonia (ICD 10.90), arachnoid cyst (ICD G93.0) and hypoplasia in the Corpus callosum (ICD Q04.0).

For treatment purposes of his MDS, a Hickman catheter / Hickman line was implanted. He also received stem cell transplantation after cytostatic conditioning. Due to his mirage syndrome, he currently has mental and developmental retardation and MRT-alterations. He is receiving hemic and neurological treatment and physical and logopedic therapy. He is receiving oncological treatment for regular clinical monitoring and control of his hemogram.

2. Questions regarding therapy and treatment

- a) Is treatment of children of four years and older suffering from **Mirage syndrome (Ataxia-pancytopenia Syndrome) with a mutation in the SAMD9L-gene** possible in Georgia?
- b) If yes, what kind of treatment would be administered?
- c) Is treatment of children of four years and older suffering from **acute myeloid leukemia (AML)** possible in Georgia?
- d) If yes, what kind of treatment would be administered? Would it be possible, in particular, to receive treatment through chemotherapy or stem cell transplantation?
- e) Is treatment of children of four years and older suffering from **myelodysplastic syndrome (MDS) with hypocellular and refractory cytopenia** possible in Georgia?
- f) If yes, what kind of treatment would be administered? Would it be possible, in particular, to receive treatment through stem cell transplantation?
- 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)?**
- h) If yes, how would the conditions as stated in g) letters a to d be treated in Georgia?
- i) Are follow-up examinations possible and what kind of follow-up examinations would be possible for
 - a. **Mirage syndrome (Ataxia-pancytopenia 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)?**
- j) What costs would arise from the treatments for the conditions as described above in letters a) to i)? Will the costs be covered by the State Health Care system or other institutions? Will the costs be covered 100% or what percentage of the costs would be covered?

Thanking you in advance for your kind cooperation I rest at your disposal for any further questions that may arise.

Kind regards,



Christian Gruttke, KS I