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To whom it may concern

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Reimbursement of the costs for medically required enteral nutrition support for infants and children in Bulgaria

It was brought to my attention that the costs for medically required enteral nutrition support for infants and children in Bulgaria are generally not covered or reimbursed, leading to serious consequences due to maltreatment of sick children that require such support but whose families do not have the means to pay for it and cannot afford to provide for meeting the needs of their sick children.

Adequate nutritional supply is an essential prerequisite for supporting the rapid growth and development of children, both in health and disease. Ample medical evidence shows that in children, not providing adequate nutrition rapidly results in states of malnutrition with severe adverse consequences not only for immediate health outcomes, for example increased risk of infection and mortality. In addition, malnutrition in childhood has severe lasting adverse effects on later health and performance, for example with respect to physical strength, cognitive abilities, and work capacity.

In Europe, the disease associated malnutrition is the most common cause of children not meeting their nutritional needs. Disease associated malnutrition can occur in children that are unable to eat enough normal food to meet their needs, for example due to swallowing disorders, neuromuscular disease, cerebral palsy after birth asphyxia, developmental disorders, and other causes. It may also result from markedly increased energy requirements that the child cannot compensate for by eating more food, for example due to congenital heart defects with large shunts that cause much increased work of the heart, certain lung diseases such as cystic fibrosis that lead to markedly increased work of breathing, or metabolic diseases that markedly increase

energy expenditure such as respirator chain defects. Moreover, a small proportion of children cannot tolerate normal foods but requires special dietary products to support health, for example due to rare inborn errors of metabolism, or food allergy such as cows' milk protein allergy. In all these affected infants and children, the provision of medically indicated, targeted enteral nutrition support is an essential need that the healthcare system should provide.

The United Nation's Convention on the Rights of the Child, adopted in 1989 and ratified by the Republic of Bulgaria with resolution of the Grand National Assembly on 04 November 1991, stipulates in article 24 that children have the right to enjoy the highest attainable standard of health, and to facilities for the treatment of illness and rehabilitation of health. It further states that parties shall strive to ensure that no child is deprived of his or her right of access to such health care services. Article 23 also stipulates that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community, and it recognize the right of the disabled child to special care. It also indicates that assistance required to meet the special needs of a disabled child shall be provided free of charge, whenever possible, taking into account the financial resources of the parents or others caring for the child. Such assistance shall be designed to ensure that the disabled child i.a. supports child's achieving the fullest possible social integration and individual development. There can be no doubt that for those children that are mentally or physically disabled by a disease that requires special nutritional support, this nutritional support needs to be provided free of charge just like other essential medical needs (the families financial resources make such support unnecessary), for the child to achieve the fullest possible social integration and individual development,

My country, Germany, has established binding regulations for covering the costs for medically indicated nutritional support of infants and children, such as special dietetic products, feeding and gastrostomy tubes, feeding pumps, and dietetic consultations for defined indications, to 100% by the public health insurances without any costs for the family, provided these are prescribed by a competent medical doctor. The health insurances have the right to review and challenge the indications and the choice of products, in order to prevent inappropriate prescriptions, which however is not an appreciable problem in practice.

I wish to encourage the responsible decision makers in Bulgaria to establish reimbursement of essential medical nutrition support for infants and children in need, following the spirit of Nelson Mandela, who as President of the Republic of South Africa said on 23 April 1997:

"Let us reach out to the children. Let us do whatever we can to support their fight to rise above their pain and suffering."

Sincerely yours



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