First Children’s Hospice in Georgia

Report N1
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First Children's Hospice in Georgia
The hospice is a place where people with incurable disease get palliative care services. The palliative care is all about improving quality of lives of those who are terminally ill and whose unfortunate fate is already determined.

Children’s hospice is a place (homely atmosphere) specifically designed for the children (0-18) who are not expected to reach adulthood due to incurable disease. The basic concept of Children’s Hospice is to create friendly and comfortable atmosphere, where in addition to caring personnel great importance is attached to the environment and interior.

At the moment when kids and their parents realize that there is no way to cure the disease, palliative care plays the huge role in mitigating psychological, physical, emotional situation. Hospice team tries its best to make kids happy, alleviate pain and help their dreams come true.

Unlike adults, children with need of palliative care require a bit different approach. First of all, children’s palliative care is oriented towards the family. It is better to start palliative care as early as possible, since it is more effective for a child, as well as for his/her family members. It relieves pain and emotional overload, which makes it difficult for the child and his family to deal with and fight against severe diseases.

The basic concept of Children’s Hospice is to create friendly and comfortable environment for children, where in addition to caring personnel great importance is attached to the environment, interior, name of the hospice and all those details that ensure a harmonious adjustment of a child to a new facility. “Dream House”, “World Map”, “Hunting of Stars”, “Beyond the Rainbow”, “House of Hope” – these are the names of hospices in different countries.

The main goal of the hospice is to create a family-type environment. Therefore, in many European countries, hospices are arranged in small, maximum three-story buildings. There are many successful examples of children’s hospices in the world. In this regard, countries with great experiences are the Netherlands, Germany, England, America and Romania. There are hospices, which resemble the house of one of the literary character or an imaginary universe.

The idea of establishing Children’s Hospice has emerged after the survey conducted in 2013, which assessed palliative care needs of children. As survey results prompted, annual statistics for children with palliative care need is 839 children from 0 to 18 years old.

Since 2015, Children’s Hospice, a non-governmental organization funded by OSGF, has been providing home care service for pediatric palliative patients free of charge. Office for home care services is free of charge from Medical Corporation “Evex”.

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Home Care for Palliative Care Kids

Home care team strives to improve the quality of life of the children and support their family members. The interdisciplinary team has received specialized trainings abroad and includes doctors, nurses, pharmacist, a social worker, a psychologist, a dietitian, and several volunteers.

Home Care Team

We (a team of trained nurses and doctors) provide home care service for palliative care kids 0-18 y/o Hot-line number is +995 570 707 757. We provide service for free.

Our home care team will make all the efforts both to improve life quality of children needed palliative care and support their family members.

Together with your child’s health care providers, palliative care professionals will work with you and your child to make a care plan that is right for your child, your family, and you. The team will help you and your child include pain and other symptom management into every part of your child’s care.

Home care team includes the professionals who get trainings in Georgia and abroad with the support of Open Society Georgia Foundation.
Study Tours in Romania, Belarus, Holland and Madrid

In 2013 the doctors and in 2014 the nurses of our team participated in intensive two-week study tour and qualification raising course at a hospice "Kasa Sperante" in Brașov, Romania.

In 2014-2015 doctors of our home care team have participated in study tours in Holland and Spain.

In Holland doctors were familiarized with the work of three leading children’s hospices and home care service and have taken intensive study course in children’s palliative care.

Doctors visited department of children’s palliative care at Nino Jesús University Hospital for children in Madrid, Spain and learned specificity of home care service.

In 2016 our nurses and coordinator have participated in study tour at children’s hospice in Minsk, Belarus.

Effectiveness of Pediatric Palliative Homecare in Reducing the Need for Hospital Care

Background

The objective of the study was to test the effectiveness of pediatric palliative homecare in improving the quality of life for its beneficiaries and their families. One of the most important factors for such families is how often the children need medical care and how many days they spend away from home due to hospitalization.

Methods

A questionnaire was created for 15 patients, who have been enrolled in palliative homecare for at least 3 months. The questions compared how many ambulatory or stationary visits to hospitals have been conducted since joining palliative homecare, as opposed to the same length of period before. The data was analyzed with a one-tailed, paired t-test.
Results

Ambulatory visits: There was a significant decrease of ambulatory visits since joining the homecare; \( p = 0.049 \). Children have needed on average 1.4 visits since joining, as opposed to 4.9 before (in the equal time period).

Stationary visits: There have been 0.5 stationary visits on average since joining the homecare, which is significantly less than 2.3 visits before; \( p = 0.024 \).

Days spent in stationary care: The amount of time spent in a stationary in a 3-month period averaged 2.1 days since joining the homecare, which is also significantly less than 13.0 days before; \( p = 0.037 \).

Conclusions

Homecare service is an important part of pediatric palliative care. The results confirm that the service provides some relief for children with the need of palliative care as well as their families. The analysis shows that the amount of hospital visits have decreased significantly for children who joined the homecare service, and so has the average number of days spent in stationary care. The study concludes that the project has been effective in reducing the need for medical care for children with palliative diseases, which is very important because the beneficiaries are subjected to less stress and can spend more time with their families.

Visit at hospices in Holland

In May, 2015 Open Society Georgia Foundation organized the working visit for a group of 8 people (Counselor to the president of Georgia, representatives of Open Society Georgia Foundation and Medical Corporation "Evex", hospice coordinator and project architect) at hospices in Holland.

During these visits at hospices they get familiarized with the concept and architecture of hospice and specificity of fund raising strategy and home care services. Gained experience will be applied during the working process at Tbilisi Children’s hospice.

First Lady of Georgia and Open Society Georgia Foundation visited hospices in Germany

On 15-18 May First Lady Maka Chichua visited two children’s hospices in Germany – “Sunny Garden” in Berlin and “Bear’s Heart” in Leipzig - together with OSGF representatives. They also met with Dr. Feist, a Bundestag member, who has supervised the Leipzig hospice since its foundation as a member of the Bundestag Health Committee.

The visit aimed to look into the children’s hospice operation system and learn from German experience.

“Learning from German experience is rather important to us. Tailoring the project maximally to the model is also important. All of us should support these children. I would like to thank once again the people that have laid the foundation for the program in Georgia”, said the First Lady after visiting the hospice.
Groundbreaking of First Children’s Hospice in Georgia

On October 10, Open Society Georgia Foundation hosted the groundbreaking ceremony to celebrate the construction of the first Children’s Hospice in Georgia. This was an idea born several years ago that became possible with the help of business partner Medical Corporation "Evex", the President of Georgia Giorgi Margvelashvili and individual donors.

On the evening of groundbreaking day, the President of Georgia hosted the reception that brought together existing and potential donors, civil society representatives, artists who have donated their paintings, embassies and international organizations.

How Hospice Will Work

Construction of Tbilisi children’s hospice is planned to be completed by the end of 2016. It will provide 24/7 care on the premises along with the day care and home care services.

The hospice will work in three main areas: a 24-hour service for about 12 kids; a day-care center, where children will be able to stay from morning till evening with their parents to get necessary services and a home care service.

We will provide service for free.

The building is being constructed in village Dighomi at 200 meters distance from Aghmashenebeli Avenue.

• Floor - 3;
• Wards for 24/h services - 12;
• Reception;
• Kitchen;
• Room for parents;
• Room for day care center;
• Room for art therapist and phycologist;
• Rooms for doctors, nurses and care givers;
• Meeting Room;
• Playing Room;
• Room for physiotherapy;
• Special place for drugs;
• Room for sterilization;
• Bathrooms;
• Laundry;
• Morgue;
• Polysensory therapy room/Snouzeling Room
On What Stage is the Construction Process?

Existing Construction
16th of May 2016
2 floors are constructed, cement covering works of third floor are on-going

Building after Construction with three terraced gardens

* Construction of Tbilisi children’s hospice is planned to be completed by the end of 2016.

Our Friends/Donors

The groundbreaking of the first children’s hospice took place in fall 2016 with the support of the Open Society Georgia Foundation in partnership with Medical Corporation “Evex”.

The first donation came from the Georgian Presidential Reserve Fund. Architectural project and design of the building has been selflessly prepared by a leading architect.

Many of the donors have chosen to contribute with monetary donations, while some local business companies have helped with construction materials and supplies. We also welcome donations of specialized furniture and appliances. More information about the hospice and donations is available at www.childrenshospice.org.ge.

If you need further information about the hospice or decide to make the donation via web site please visit www.childrenshospice.org.ge

Web site and web page of Children’s Hospice are visited by a lot of users where they can find the letters of thanks to those who help us. Besides, we would like to allocate different rooms in hospice to donors. For example: room #1 (ward) for children from the “Bank of Georgia”, Yard: - for children from Nino Kiknadze etc.

By the end of 2016 we plan to organize official opening of hospice because it will be the first Children’s Hospice in Georgia. Media (printing media and TV) is very interested in this issue and regularly makes updates about it on TV. For example, ceremony of laying foundation for Children’s Hospice and reception have been broadcast by all TV channels in Georgia.

Naturally we publicize the names of donors only in case of their written consent.

Our friends: Georgian Presidential Reserve Fund; Open Society Georgia Foundation; Medical Corporation “Evex”; Giorgi Chkonia and Ruso Lashkhi; “Adjara Business Group”; Temur Ugulava; Mikhno Svinomishvil; Giorgi Ramishvili; LTD “Dio”; “Heidelbergcement”; HeidelbergBeton Georgia; Staff of the “Curation International Foundation”; Giorgi Gotsadze; Keti Chkhatarashvili; Tamaz Somkhishvili; Elen Vasilets; Khoifiz Shahid; Armen Matevosyan; Archil Gachchiladze; David Vakhantishvili; Artandil Namicheishvili; Irakli Burdiladze; Giorghi Tchiladze; Vasil Khodeli; “Gvinadze and Partners” LLC; Gaga Margvelashvili; LTD “Toyota”; JSC “Telasi”; Ani Akhalkatsi; Ann Toklikishvili; IDS “Borjomi Georgia”; Tamar Neparidze; Giorgi Ramishvili; Gia Jokhtaberidze; Konstantine Matitashvili; Ketevan Tutberidze David Gzirishvili; “Eurasia Trans” LTD; “GeoStell LLC”; Irakli Rukhadze and his friends.

Special Thanks to: Mary Callaway; Joan Martson; Nikoloz Gamkrelidze; Keti Khutsishvili; Nino Chichua; Giorgi Abashishvili; Sophia Shamanidi; Giorgi Juruli and Vaniko Bokeria

Artists: Maka Batashvili; Tamar Shuakashvili; Zurab Gomelauri; Anton Balanchivadze; Nino Chakvetadze; Papuna Papaskiri; Kato Akhalkatsishvili; Tutu Kiladze; Mamuka Gogritchian; Nino Kalandia

We would like to thank also that our friends/donors who prefer to remain anonymous. Many thanks to hundreds of individuals that have contributed 1 GEL for building the hospice.
Various Charity Events for Hospice

The company “DIO” dedicated its 20th anniversary to children’s hospice and donated high-quality doors and windows, tents and shutters to hospice.

Mr. Tamaz Daoshvili, Director of LTD „Dio” and Keti Khutsishvili, Executive Director of Open Society Georgia Foundation

A friend of Hospice - Irakli Rukhadze’s 50th anniversary organized in favor of Children’s Hospice

„If you think about my birthday gift, the best present would be a donation for the construction of 1st Children’s hospice in Georgia!“ - Irakli Rukhadze’s nearly 150 guests received an invitation card with above-mentioned content and a considerable sum of money has been gathered with their support. This sum of money will be used for construction of hospice.

Run for Children’s Hospice! Heidelbergcement is organizing “Tbilisimarathon” on October 22nd

This year “Heidelbergcement” is planning the social project “Tbilisimarathon” for the fifth time. The project serves to promote healthy lifestyle and charity work. “Tbilisimarathon” is organized with the support from the German Embassy in Georgia, Tbilisi City Hall and Ministry of Sport and Youth Affairs of Georgia. Participants include guests from over 30 countries, diplomatic body as well as government and business sector. The funds raised from the registration will be doubled by Heidelbergcement and donated to the construction of Children’s Hospice. Registration for “Tbilisimarathon 2016” is now open.

Register and Join us: www.tbilisimarathon.ge

Currently (1.06.2016) about 600 000 GEL has been mobilized into account

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Reporting to Donors

In order to ensure sustainable funding from donors the Foundation keeps donors in the loop and keeps consistent communication starting from expressing appreciation and gratitude ended up with keeping in track of resource allocation. The transparency of donations is ensured in a way that the Foundation sends regular updates to two main partners and the Hospice Executive Board. Notifications upon each new transaction are sent to all relevant individuals.

Project financiers participate in all activities organized for hospice support. Each donor of the project will take part in an opening ceremony of hospice. News about hospice is regularly published on hospice web page and FB page.

Approve our FB page and make friends with us: Home care for children with need of palliative care.

Web-page:  www.childrenshospice.org.ge

What kind of help is needed?

Most part of money for construction has been already collected. Nearly 220 000 GEL is needed for finishing the construction. Based on concept and requirements of hospice it is important to make court yard, obtain equipment, furniture and technique that is quite costly part of the project.

At present fundraising activities are on-going for establishing of Polysensory therapy room/Snouzeling Room that has therapeutic, relaxing, cognitive and detoxication functions.

Budget for arranging a room is between 15 000 and 18 000 Euro. A room includes:

A room where children experience new external stimuli, learn colors, sounds, shapes and texture of materials, which helps calm down and limit the fear of the world in mentally disabled children. The children may join all those stimuli by stepping on a special landing which lights up and emits sounds or using the sensory panels to get to know the surrounding space.

Musical Hydro Bed - implies bag-like mattress that provides the effect of intensive waves. Hydro bed is equipped with electric heater and thermostat generating water with 28 degree temperature.

CD player with radio is installed in a bed.

A bed makes different movements, creates swinging effect and provides perception of various sound effects by body. Hydro bed is a stimulatory element for keeping balance and makes available to perceive own weight by body. Swinging helps to relax joint muscles and relieve body. It is ideal after chemotherapy. Hydro bed is also used for sea thematic tasks; it can create the effect of storm, thunderstorm and swimming.

Water and Light Curtain (on the photo it is near a mattress)

It is colored equipment fastened either to ceiling or a wall. It is used as illuminated wall and is separated from other objects located in a room. It is possible to place it in front of a bed thus creating the isolation effect and at the same time provides space visibility of a whole room.

The curtain is used for eyesight stimulation. It improves tactility.

Maka Chichua First Lady at Children hospice in Germany

Bubble Tube - Bubble Tube is installed in a safe reservoir.

The equipment makes possible to change colors and to modify pace and amount of bubble flow by means of voice, and touch. It is possible to change colors (there were 16 colors in a hospice in Spain) and their duration, illumination degree, pausing, to select different flows of bubbles.

Bubble tube creates a pleasant visual and sensibility feeling. In its lower part oxygen is produced that facilitates formation of bubbles which slowly move upward through different colors. The child chooses desired color by means of buttons placed on a special panel.

The equipment stimulates eyesight. It is also the best stimulator of feelings; child can entwist it by a whole body.
**Gymnastic balls of different sizes**

It is possible to sit on them, lie face up or downward, lean against it or jump. Ball exercising facilitates to stabilization, progressive engage of muscles and activates postural muscles. It is very also very effective for children with cerebral paralisys.

**Pool/Jacuzzi with interactive balls**

The LED Interactive Ball Pool is illuminated by a very bright low-voltage LED that never needs replacing. The color is always vibrant, and cycles through eight different colors when activated. Press any of the colored switches on the walls to change the light, and the balls, to the corresponding color. The pool is made from strong, easy-to-clean phthalate-free vinyl. Balls are sold separately. Choose from medium or large pool size. The product typically ships 6-8 weeks following order date.

**Price starts form:** - $4,449.76

**Beds**

We are in need of 12 special beds that might be necessarily made of wood. In total 10 000 dollars is required for beds.

**FINANCIAL SUPPORT/DONATION**