



Edita Abrukauskienė with her daughter Rugilė, in the spring of 2002.



Rugutė – helping those who need it most

Text: Ray Vyšniauskas

IN LIFE, AS IN THE MAGAZINE BUSINESS, it seems it is all too easy to overlook the many good things in life, and focus much more easily on the negatives. While we often look at the central figures in Lithuanian life and place them at the centre of our attention, more often that not it is the unknown or unheralded individuals that go about their business with modesty and humility, without looking or asking for fame, that deserve the most attention. This is the essence and pride of Lithuanian life that too often passes unnoticed. Just such a person is Edita Abrukauskienė, the founder and director of the Rugute Foundation.

Sadly Edita Abrukauskienė is one of too rare a breed in Lithuania. She shies away from publicity unless forced to for her work, and prefers to gauge her achievements through actions rather than empty promises which is more often the case.

Edita Abrukauskienė, along with husband Dainoras Abrukauskas started the Rugute Foundation, or legally entitled The Childhood Cancer Fund Rugute, four years ago in November 2004, as a non-profit, non-government organisation.

Rugute Foundation supports children suffering and having suffered, or in remission from cancer. The Foundation's activity is aimed at creating a better understanding of the ramifications when young patients and their relatives hear the terrible diagnosis of cancer.

Through the Rugute Foundation they can receive both spiritual and financial support, understanding, and all the relevant information about the treatment of oncological diseases and the necessary ongoing care.

RUGILE ABRUKAUSKAITE

The name of the Rugute Foundation comes from Rugilė Abrukauskaitė, Edita's daughter, who was better known as Rugutė. On 26 August 2002 Rugilė was diagnosed with a malignant tumour called yolk-sac tumour. Rugutė fought the disease for almost two years until her death on 10 April 2004. Rugutė was one of about 100 children who contract some form of cancer in Lithuania each year.

"It was during those two years that we realised the lack of treatment and information available to sufferers of

cancer in Lithuania, and especially for children. There was almost nothing available and we wanted to help others so they didn't have to go through the terrible grief and mystery that we were faced with during Rugutė's treatment," Edita said.

"Hearing that your child has been diagnosed with cancer is probably the most horrifying thing in the world, you feel so helpless. With nowhere to turn you feel like you are all alone, and that no-one can help you. Added to the lack of general information about the disease and treatment, it was the most frightening time of our lives."

After Rugutė died, Edita and her husband Dainoras were inspired to ease the pain for everyone else who found themselves in the same situation. Their initial aim was just to provide information, and to set up a website which would supply all the facts and assistance that they found so badly lacking when they needed it most.

"The idea was to guide others through all of the uncertainties that we had experienced, but as we got more involved the project just grew and grew. We met others who are going through exactly the same as we did, and you realise that often they just want someone to talk to, they need some personal contact. They want to try to understand what is happening, knowing that their children are relying on them, but they are feeling just as helpless as we did."

To say that the project grew from that simple idea is an understatement. Today the Rugute Foundation directly supports about 50 families where children suffer from various forms of cancer. Their support ranges from the provision of Lt300 as a small help to cover the added expenses during time of illness, to the setting up of special funds of

and support for children with specific conditions which require expensive treatment, or sometimes the need to travel to other countries to be properly treated, and which can easily add up to over Lt100,000.

The latest initiative of the Rugute Foundation is the setting up of a small unit near the Santariškes Hospital. They have just rented a small two bedroom cottage which they have renovated and are now beginning to furnish.

“It is a concept used overseas - providing accommodation for families who need to travel to the city to visit their children who are undergoing treatment. It gives the family somewhere to stay and just takes another worry out of caring for their child. It has a kitchen and playroom where the family can spend quality time together.



“We hope to build our own bigger house in the future, rather than having a rented premises as we do now. But that is a long way into the future,” Edita said.

DONATIONS

In 2006 the Rugute Foundation was brought to the attention of Lithuania and producers of the TV3 television project *Lietuvos Garbė* (Lithuanian Honour), and they presented Edita Abrukauskienė the award of Benefactor of the Year.

“I don't like publicity, but realise it is necessary. After the TV show we became much more widely known.

“Most of our support comes from individuals and anonymous donations, as well as some businesses, and we are always inspired by the number of good people out there who help us.

“Last weekend in Ireland the children from the Lithuanian communi-

ty over there have all made things for sale at their local Kaziuko Muge (Casimir's Fair), and all the proceeds raised will be donated to the Foundation,” Edita said.

In May 2006 the Fund established close contacts with the Lithuanian Embassy in Japan and the Japanese-Lithuanian Friendship Association. The Embassy of Lithuania in Japan started spreading the word about the Rugute Foundation and helped find new sources of financial support far from Lithuania, as well as providing the love that all children need.

Rugute also maintains close ties with the Lithuanian diplomatic missions in Sweden, the Russian Federation, France and Turkey. It has ongoing projects with foreign non-government organisations. From 26 May to 1 June 2007, Simona, who is a benefactor of the Foundation, has participated in the International Week of Children with Leukemia organised by the LOSEV Foundation in Turkey.

Rugute also greatly appreciates the support coming from representatives of the Lithuanian community in the United States, as well as from warm-hearted friends in Sweden. Mr Bengt Nilsson, who's daughter successfully defeated leukaemia, offered his generosity to the Lithuanian children. Just before Christmas Mr Nilsson came to Lithuania, together with a minivan full of gifts from Swedish children to the little patients at Vilnius and Kaunas hospitals.

At present the Fund helps directly support about 50 families. The age of the children under treatment or in remission is from 1 to 18 years.

Apart from Edita and her husband, the Rugute Foundation has a number of volunteers who assist the foundation within their particular abilities and skills. These volunteers visit sick children and their families, explain and translate given material about children's oncological diseases and special care from foreign lan-



Christmas wishes come true - Edita and volunteers visit children at Christmas time.

guages, edit texts and actively search for financial support.

The foundation's website - www.rugute.lt - also serves to provide information to patients and their families about children's oncological diseases, patient care and psychological problems that can occur in the course of treatments. It also details the lives, conditions and progress of sick children or children in remission. It is a forum for sharing experiences, asking questions of volunteer medics, expressing feelings and discussing various social and care-related issues.

It is also the means of showing donors how their money is being used and ensures the full transparency of the Rugute Foundation, which also supplies monthly reports of all donations received.





Dainora's wish to meet the popular singer Vilija came true...

ACTIVITIES

It's usual at this point to say that the Rugute Foundation has helped countless children and families and leave it at that, but their work has been so widespread and varied that I think it's important that we list at least a part of the great work they do.

Social Support for Families

The Foundation supports families by providing food, special equipment and the special medicines necessary in the course of cancer treatments, which in the case of children is more often very long and difficult, sometimes lasting for years. Protecting the patient's rights for quality treatment and ensuring the availability of modern and effective procedures, the Foundation pays for individual consultations or partially covers the expense of treatment in foreign clinics, depending on the circumstances of the family.

Making Dreams Come True

One of the most heart-warming missions of the Rugute Foundation is to fulfil the dreams of sick children, and they yearn for many and various things. Some want radio-controlled cars, others PlayStations, bicycles, laptop computers, painting easels or guitars. Some wish to be a police officer for a day or meet their favourite pop stars. In December 2006 one young girl, Dainora, wanted to meet popular singer Vilija Mataciunaite. Vilija agreed, and visited Dainora in hospital making the sick girl smile even during her most difficult and painful days. Dainora died on New Year's night that same year.

Accumulation of information on Childhood Cancer

The Foundation pays particular attention to the preparation and spreading of information on children's cancer, or oncological diseases, and care for the families of the sick children. All information is prepared and published on the Foundation's website - www.rugute.lt. Detailed and timely information about specific forms of cancerous diseases is of enormous importance.

EVENTS

Japanese Culture Days

The Foundation has been co-operating with the Lithuanian Embassy in Japan and Japanese-Lithuanian Friendship Association. During the Japanese Culture Days, which took place on 23 - 24 March 2007 in the National Drama Theatre in Vilnius, an effort was made

to improve the quality of treatment for Lithuanian children with oncological diseases supported by the Japanese people and their friends. More than 100 Japanese performers gave their services free of charge to the lovers of Japanese culture, and invited the audience to make a donation to help the children. The money was used to buy vital medical monitoring equipment invaluable in the diagnostic magnetic resonance tests of children at Kaunas Medical University Hospital. This hospital provides treatment of oncological diseases of the central nervous system for patients from all over Lithuania. The Foundation donated Lt76,923 to the Kaunas Medical University Hospital.

An Island of Friends

On 14 October 2006 the Foundation organised the first annual meeting of over 30 families affected by cancer, which totalled about 100 people. Oncological diseases and their treatment is complicated and involves difficult procedures, touching on all aspects of a child's life: physical condition, psychological comfort, as well as relationship with family members and friends.

The aim of that meeting was to gather families sharing similar circumstances, to encourage them to share social and medical information, experiences, thoughts and feelings. The meeting started with a Mass in the St Bernardine Church, and continued at the Belmontas entertainment and rec-



recreation centre. Actors from the Keistuoliu Theatre performed their musical: Joseph and the Wrap of his Dreams. The knights of the Order of the Northern Temple demonstrated a medieval battle. On 30 June 2007 the second such event took place. This time it attracted about 150 participants. The Mass at St Ignatius church was followed by a beautiful celebration of friendship at Sesuoletiai manor house. The Foundation hopes that these meetings will become a beautiful annual tradition.

Christmas is a Time of Miracles

Each year the Foundation organises a traditional event entitled: Christmas is a Time of Miracles; during which volunteers from the Foundation visit and give Christmas gifts to the children all over Lithuania helped by the Foundation.

Droplet of Blood

The Foundation invites everyone to follow its example and give a drop of their own blood for children with the oncological diseases, as well as to become active members of blood donation programs.

Spread of information

Daily newspapers, magazines and internet websites from time to time feature the problems of children with oncological diseases, their joys, strength and concerns. In this way the Foundation's aim is spread, and knowledge of the Rugute's noble activities is increased as society is informed about the plight of children with cancer.

Special Appeals



The Foundation also uses a lot of its resources in helping individual children and their parents and families. Over the course of the previous years they have raised special actions which have raised money for particular treatments, including the provision of drugs that have as not yet been listed on Lithuania's subsidised medicines list, and which provide the most effective treatment of particular conditions, though at costs prohibitive to individuals.

Other actions have raised money that has been used to pay for treatment of children in other countries, when the facilities and procedures are not available in Lithuania. The Rugute Foundation has paid the majority of expenses of children who have been treated in France, Canada and Germany, among other countries. These special actions have raised amounts of up to Lt100,000. ■



Contacts:

Childhood Cancer Fund Rugute
 Edita Abruškauskienė, Director
 P. Smuglevičiaus g. 45
 LT-08311 Vilnius, Lithuania
 Mobile: +370 620 69665
 E-mail: info@rugute.lt
 www.rugute.lt

