



Raisa Gorbachev Foundation  
Combatting Childhood Cancer

# impactupdate

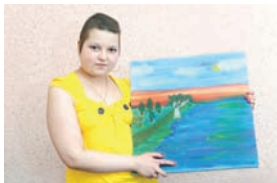
Autumn/Winter 2010



The Raisa Gorbachev Foundation raises funds for the detection, treatment and control of childhood cancer. The foundation aims to improve access to life-saving treatments for young patients.

*working together to help children affected by cancer*

**Nastya** was 10 when diagnosed with leukaemia. Her life has been punctuated by therapies and relapses. A talented, creative child who loves art and drawing, in hospital she learned computer graphics, started oil painting and piano lessons. When she feels sad she writes poems or dances. "When I do something I like I feel better and more balanced", she says. This year she required advanced treatment not available in Russia; this was provided by the Foundation. Nastya is now in hospital feeling strong and ready to fight the disease.



**Elliot and Leon** were only 7 and 10 in 2007 when their mother, Fran, was diagnosed with terminal cancer. After her death Allison, a Marie Curie bereavement

counsellor, has been helping them to talk, to heal and to keep their mum close to them by creating their own personal memory books. Now, 3 years later, the boys are showing signs of resilience and

strength. They can talk openly about their feelings and at Christmas they still go back to the Marie Curie Liverpool Hospice and post homemade Christmas cards for their mother in the special box placed there for messages to loved ones who have died. The Raisa Gorbachev Foundation funds the Marie Curie bereavement counselling programme in a quarter of all Marie Curie hospices.

**Maxim** no longer needs treatment. Only days after he was born, Maxim was diagnosed with a rare disorder only affecting boys. A genetic mutation, the result of an unusual combination of his parents' chromosomes, was a serious threat to his life and future. A bone marrow transplant was his only chance. The Foundation made this possible. Now Maxim is a healthy, energetic boy. He still visits the Raisa Gorbachev Memorial Institute in St Petersburg where he received his treatment.



"Treatment of young patients with oncological diseases still represents a quite urgent and relevant problem. We provide new hope for many families and this help saves lives. I would like to give my sincere thanks to everyone who has responded to our appeal for support."

Mikhail Gorbachev

## A MESSAGE FROM THE CHAIRMAN

The devastating news that their child has cancer is delivered to dozens of families in the UK and Russia every day. The diagnosis of cancer is the start of a terrifying journey, but one which increasingly has positive ends.

Continuing developments in diagnosis and treatment mean that patient outcomes are constantly improving and mortality rates are dropping.

To meet brave young patients who are fighting for their lives as well as the teams on whose expertise they totally rely is not just an inspiration, it is testament to the real impact that we can all have on these lives.

Nothing can stop children falling ill with cancer, and we will continue to help in any way possible to ease the burden on families and children faced with the disease.

The Foundation's Russian Midsummer Gala raised more than £1.7million in June – every penny of which will be used to develop and expand the reach of the Foundation. In these times of economic uncertainties, this achievement is a wonderful testament to our supporters, whose generosity is extraordinary.

We aim to achieve maximum impact with every grant we give, whether it is responding to a child in desperate need of medicine, critical training of doctors and nurses, provision of pioneering equipment or supporting research into life-saving and life-enhancing solutions. Now more than half of the grants are focussed on projects in Britain.

Thank you our donors, sponsors, volunteers, partners and foundation team. Your combined efforts, generosity, devotion to our cause will continue to change those young lives that so urgently need it.

Evgeny Lebedev, Chairman

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Evgeny Lebedev, Mikhail Gorbachev and Alexander Lebedev at the 5th Annual Russian Midsummer Gala

## WHAT WE DO

The Foundation has identified five areas to maximise the use of the funds we raise for our Cancer Control and Beyond Therapy programmes. As the Foundation develops, the geographic reach is increasing. It is our aim that every grant awarded has a global application and world-wide implications.

### Therapy

funding treatments when financial barriers stand in the way

### Research

investing in innovative approaches to combat and control cancer

### Equipment

furnishing institutes with essential equipment and infrastructure

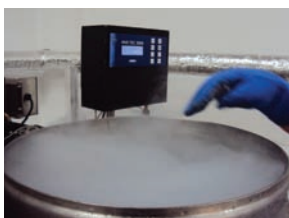
### Advocacy

influencing key players and promoting better understanding

### Training

investing in those professionals who make a real difference

These targets guide the grant distribution process. For more information on the grant process, see the Foundation's website [www.raisafund.org.uk](http://www.raisafund.org.uk).



## Denis (2) and Artyom (8)

Denis and Artyom are being given a chance to live through the combined efforts of the Raisa Gorbachev Foundation and the Raisa Gorbachev Memorial Institute in St Petersburg. A bone marrow transplant is the only way to treat their diseases. The international search for an unrelated donor was funded by the Foundation. Two-year old Denis's match was found in April and he is now home. His last visit to the Institute showed healthy blood results. Our search continues for a match for 8 year old Artyom who is in relapse for the third time. He has lived in the hospital since the spring. A bone marrow transplant is his only chance.

## CANCER CONTROL PROGRAMME: Grants 2010

*Transforming the lives of those afflicted with life-threatening illnesses in the following ways*

### 1. THERAPY

New therapies now give children with cancer a real chance to live. A procedure such as a bone marrow transplant can often represent the last chance of survival for many patients.

Wherever possible, we try to respond to the needs of children suffering from life-threatening diseases. In cases where these are not provided by the State, urgent and emergency rehabilitation and treatment are funded via our partners.

The Foundation mainly helps children whose diagnosis is very difficult and whose treatment cannot be funded by the State, so not every story is a happy one. More and more frequently do we hear of success stories where the initial outlook was very negative.

### 2. RESEARCH

We are funding clinical and research teams working on the causes and early detection of cancers, different treatments and their side effects. It is our aim to commission projects which improve diagnoses and treatments, minimise effects of invasive treatment and reach more patients more quickly.

### 3. EQUIPMENT

The Foundation is completing the installation of specialist facilities and equipment at institutes at the forefront of paediatric oncological healthcare. Every year, in increasing numbers, patients with rare cancers are able to receive advanced diagnostics, treatment and post-therapy monitoring.

Later in the year two new diagnostic rooms will be officially opened in the Blokhin Cancer Centre in Moscow. These are equipped with pioneering equipment in a better, more flexible, more convenient and comfortable environment. More children can be treated and significantly less evasive procedures undertaken.

With the equipment the Foundation has provided, doctors can now harness the advances in surgical techniques, chemical and biological therapies. Patients are now treated more accurately, resulting in a better chance of cure and significantly reduced side effects of therapy.

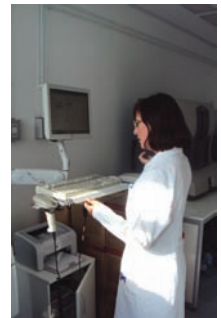
### 4. ADVOCACY

We will continue to apply pressure on those who influence policy. In April the Foundation, together with the London Evening Standard newspaper, held the first symposium on philanthropy, exploring what motivates people to give. This is an area where we will increase our activity in Russia and the UK.

### 5. TRAINING

The development of the Raisa Gorbachev Scholarship is an exciting development and will promote the sharing of best practice, information and expertise.

Doctors and nurses from Russia and the Former Soviet Union will be able to apply for a scholarship giving them a unique opportunity to gain international experience in their fields. Successful applicants will have the chance for 3 month 'clinical observerships' in the world's leading paediatric oncology centres in the UK and America.



## BEYOND TREATMENT - PALLIATIVE CARE

*Enhancing care for children when treatment is no longer an option. We aim to make life, however shortened, as pain-free, as comfortable and as manageable as possible.*

The Raisa Gorbachev Foundation supports improving all aspects of end of life care from research to care delivery to bereavement counselling. The Foundation's 'Beyond Treatment' programme is a direct response to the cross-border demand for urgent investment in children's end of life care. This is palliative care which does not concentrate on the fact that a child has a life-limiting disease; it focuses on an active approach to making that life as good as possible.

We invest in the development of innovative approaches to pain and psychological management for children when therapy options are exhausted. Our partnership with Marie Curie Cancer Care, Britain's leading providers of high quality care to those suffering from terminal cancers, helps us to ensure everything we do in this field has the greatest impact in the fight against cancer.

"Marie Curie Cancer Care is incredibly grateful for the support of the Raisa Gorbachev Foundation. The Foundation has now contributed nearly £2.5million towards our work with young people, making you one of our biggest supporters. Thank you for being such a wonderful friend to our charity - your commitment to philanthropy is an absolute inspiration."

Thomas Hughes-Hallett, Chief Executive Marie Curie Cancer Care



### 1. PIONEERING RESEARCH

The population of children and young people with life-limiting and life-threatening conditions is growing. According to the UK Department of Health, the annual number of children requiring access to end of life care services in the UK is estimated to be 23,500, yet end of life care research for children is still a seriously underfunded area. New technology has improved survival rates and enables children with a terminal diagnosis to live longer. The Foundation will fund practical research that will have a direct impact on children with end of life care needs and their families so that no child suffers unnecessarily from severe pain or other negative symptoms at the end of their lives.

**The Louis Dundas Centre at Great Ormond Street Hospital** was established in 2009 by Bruce and Ruth Dundas in memory of their son who died at the age of four from a brain tumour.

The Centre is dedicated to undertaking well-coordinated, high quality evidence-based research into paediatric palliative care and to the development and delivery of training in this specialist field. It will develop partnerships with

national and international bodies to create a stronger global voice, to raise the profile of children's palliative care and to influence policy for the worldwide benefit of children with life-threatening and life-limiting illnesses.

The Raisa Gorbachev Foundation has provided two grants towards the palliative care team in Great Ormond Street Hospital. The first is a three year grant to fund the first dedicated paediatric palliative care psychologist. The role of this person is to provide, evaluate and develop psychosocial and bereavement support for families of children with life-limiting and terminal illness. This new post will significantly improve psychological outcomes for children and families, by addressing their changing needs throughout palliative care and bereavement. A second grant has been awarded to the Centre to establish the vital role of a research associate who will work as part of this ground-breaking team.

*"The Raisa Gorbachev Foundation has made a cutting edge gift to the Louis Dundas Centre and more importantly to children with life limiting conditions and life-threatening illnesses and their families."*

Professor Bluebond-Langner - Chair, Louis Dundas Centre

## 2. DELIVERY OF CARE

With your support Marie Curie Cancer Care provides hospice and nursing care to young people with cancer in the UK.

**Nursing and hospice care for 16-25 year old patients:** Marie Curie Cancer Care is passionate about patient choice at the end of life and the fundamental right to dignity in death. We believe that everyone should have the option to spend the final weeks of their life in a familiar place surrounded by the people they love. Marie Curie nurses provide care and support to patients and families in their own homes. Grants from the Raisa Gorbachev Foundation mean that these nurses can treat and manage symptoms and give medications to relieve pain for more young patients.

Marie Curie's hospices across the UK provide in-patient care for people who often have more complex needs. The Raisa Gorbachev Foundation has already invested in new family rooms at our hospices in Glasgow and Hampstead and will be providing a family room and dedicated children's room for the brand new hospice to be built in Solihull.

### John's Story

"John was 19 when he first came to the hospice. He'd had a troubled youth and had just started to turn his life around when he was diagnosed with a brain tumour. We admitted him to help him manage his symptoms and to talk through the complex thoughts and feelings that are overwhelming for someone so young. His friends would visit every night with food and scary films, and he told us it was just like being at home. It was important for him to try and to keep his life as normal as possible right to the end and I think we achieved that. He died six months after we first saw him with his mum and his grandmother by his side."

Alison Fisher, Nurse, Marie Curie Hospice

## Development of Palliative Care Teams in Former Soviet Union

### Training and sharing good practice:

The Foundation is working closely with our UK charity partners to assist in the emergence and development of palliative care teams in Russia and Belarus. We will fund training and provide guidance to doctors, hospital directors and health departments in the establishment of hospices, home hospice teams or palliative care units.

As part of the Raisa Gorbachev Scholarship, doctors and nurses can apply for support in training and education in this underfunded and underdeveloped area. They will be offered opportunities to visit hospices, spend time with palliative care specialists and attend training courses in the UK. In conjunction with Marie Curie Cancer Care and the Louis Dundas Centre, we will give bursaries for training and development in End of Life Care for all children suffering from life-limiting and life-threatening diseases.

We have awarded a grant to the Chernobyl Children's Project to develop their amazing work in the establishment of palliative care teams in Belarus. Two doctors will be trained at the Centre of Palliative Medicine at Cardiff University as consultants in this field.

## 3. BEREAVEMENT SUPPORT

About a quarter of 5-16 year olds in the UK have experienced the death of either a sibling or close family member. The death of a parent or other close family member during childhood is one of the most stressful events that a child can experience. The emotional effects of bereavement such as intense sadness, isolation, anger and guilt can have short and long term negative psychological effects. Marie Curie Cancer Care's experienced and highly trained bereavement counsellors offer support to children between the ages of 3 to 18 throughout the illness and after the death of their loved one. The Foundation is honoured to fund this essential service.



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## RUSSIAN MIDSUMMER GALA – JUNE 2010

Mikhail Gorbachev, Evgeny Lebedev and Geordie Greig were delighted to host the fifth annual Russian Midsummer Gala at the Stud House, Hampton Court in June. The event raised £1.7 million for the Raisa Gorbachev Foundation and Marie Curie Cancer Care.



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The Foundation's accounts can be found on our website: [www.raisafund.org.uk](http://www.raisafund.org.uk)

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Certain names and photos have been changed to protect the identity of the children.

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