Let's help children get better and make their dreams come true

CHILDHOOD CANCER FUND RUGUTĖ ANNUAL REPORT ON THE RECEIPT AND USE OF SUPPORT FOR 2020

rugute.lt

Yet another year we are motivating and giving hope to those whose life has been very challenging. For sixteen years, we have been focused on helping children with oncological diseases in all possible ways. Today, when we stop and look back, we are happy with the community we have created: relatives of sick children and adult ex-patients willingly help those who have recently heard that their diagnosis is an oncological disease.

We are happy that all these years we have been able to work with doctors and contribute to the successful treatment of children, ensure the application of the most advanced treatment schemes, buy medicines and nursing equipment on time, finance genetic tests that are not carried out in Lithuania, or pay for treatment in foreign clinics. There is no doubt that a new generation of medicines, modern tests, and more advanced nursing and medical devices lead to higher cancer survival rates and long-term remission. For the sixteenth year in a row, this is the direction of the Fund's activities, because we have gone through a difficult and long path of treating our daughter Rugilė.

Undoubtedly, 2020 was one of the most difficult years in the Fund's history. When a lot of activities stopped due to COVID-19, the children's struggle with the disease continued without the slightest break. The challenges experienced in spring, when the borders of the countries were closed, will remain in our memory because we had to find a way to bring to Lithuania the medicines necessary for the treatment of Ainaras. The delivery of the medicines was delayed and eventually these medicines have disappeared. However, all the struggle was worth it, because today we are happy to see Ainaras in remission.

Still, the most appreciated evaluation form is the letters from relatives of the children who have overcome an oncological disease. This time, we want to share a letter from Kornelija, mother of Bazilė. We thank Kornelija for sharing what many people are afraid to share. We often see and support those who are on the path to healing, but we rarely think about helping those whose children are in a long-awaited remission that is only the beginning of new and not always easier struggles.

"I don't know if people whose loved ones (especially children) never had an oncological disease are wondering what the family of a sick person has to go through. The pain is indescribable. My soul and body broke into thousands of pieces, and I no longer knew if it was possible to put them together again. I think not. When Rugutė appeared on our path, some contours of my pain began to emerge and it became clearer how one can begin to move, breathe, and eat with all that pain. Rugutė raised money intended for immunotherapy, helped get all the items necessary for the treatment processes, and consulted at night when no one could provide such help any more. After the treatment, Rugutė helped to buy hearing aids and paid for almost all the necessary rehabilitation procedures and continues to help to this day. After the treatment, nothing ends, because another stage begins. It is a stage of a different life, which may be better understood by those whose children have been diagnosed with brain tumours. We are still trying to hang on: sometimes very successfully and sometimes less successfully. This side is invisible, because after an illness a history of victory is usually told, and those who are left to live with many challenges are being ignored, because no one wants to see us. We also need to be accompanied in such a situation. The Fund Rugutė is doing that, quietly and without telling anyone."

We want to thank our long-term and new sponsors, initiatives of businesses, schools, and individuals, i.e., all those who supported Rugutė's activities, for the ability to continue our activities and help children who were diagnosed with oncological diseases. We have said many times that without your support we would not be able to take a step, we would stumble, and possibly turn back. So, once again we want to state that your partnership is priceless.

Thank you for being with the children and doing it for the children.
Edita Abrukauskienė

GENERAL INFORMATION

Childhood Cancer Fund Rugutė (hereinafter referred to as the “Fund”) is a legal entity registered in the Republic of Lithuania. It is a non-profit non-governmental organization.

Registration No. 300070090
Registration date: 29 November 2004 (registered in the State Enterprise Centre of Registers)
Date of granting the status of beneficiary: 29 November 2004
Fund’s registration address: Kosmonautų Str. 3-15, Panevėžys, Republic of Lithuania
Fund’s registered office address: P. Smuglevičiaus Str. 45, Vilnius, Republic of Lithuania

Childhood Cancer Fund Rugutė was founded in 2004 by Edita Abrukauskienė and Dainoras Abrukauskas after they lost their three-year-old daughter Rugilė who was diagnosed with an oncological disease. The confrontation with their daughter’s oncological disease, the current situation of the health care system, and the lack of information in Lithuanian about oncological diseases encouraged the founders to share their experience related to complex treatment and help families affected by the child’s oncological disease.

For sixteen years, the aim of the Fund Rugutė has been to provide information, financial, medical, and psychological assistance to children diagnosed with oncological diseases, to support medical institutions where these children are treated, to collect legal, social, and medical information necessary for families affected by child’s oncological disease, and to promote the communication and sharing of experiences between these families.

The Fund also implements various social projects, initiates or contributes to support campaigns aimed at improving the quality of treatment of Lithuanian children diagnosed with oncological diseases.

When carrying out its various activities, the Fund closely cooperates with non-governmental organizations in Japan, Poland, Sweden, France, Turkey, China, and Belgium and diplomatic missions of the Republic of Lithuania in these countries, with Lithuanian communities and individuals in the USA, China, Luxembourg, Belgium, Norway, and Ireland that are interested in ensuring that every young patient receives targeted and the most efficient treatment.
The Fund provides support to children from age 0 to 18 who are being treated or have reached remission of the disease.

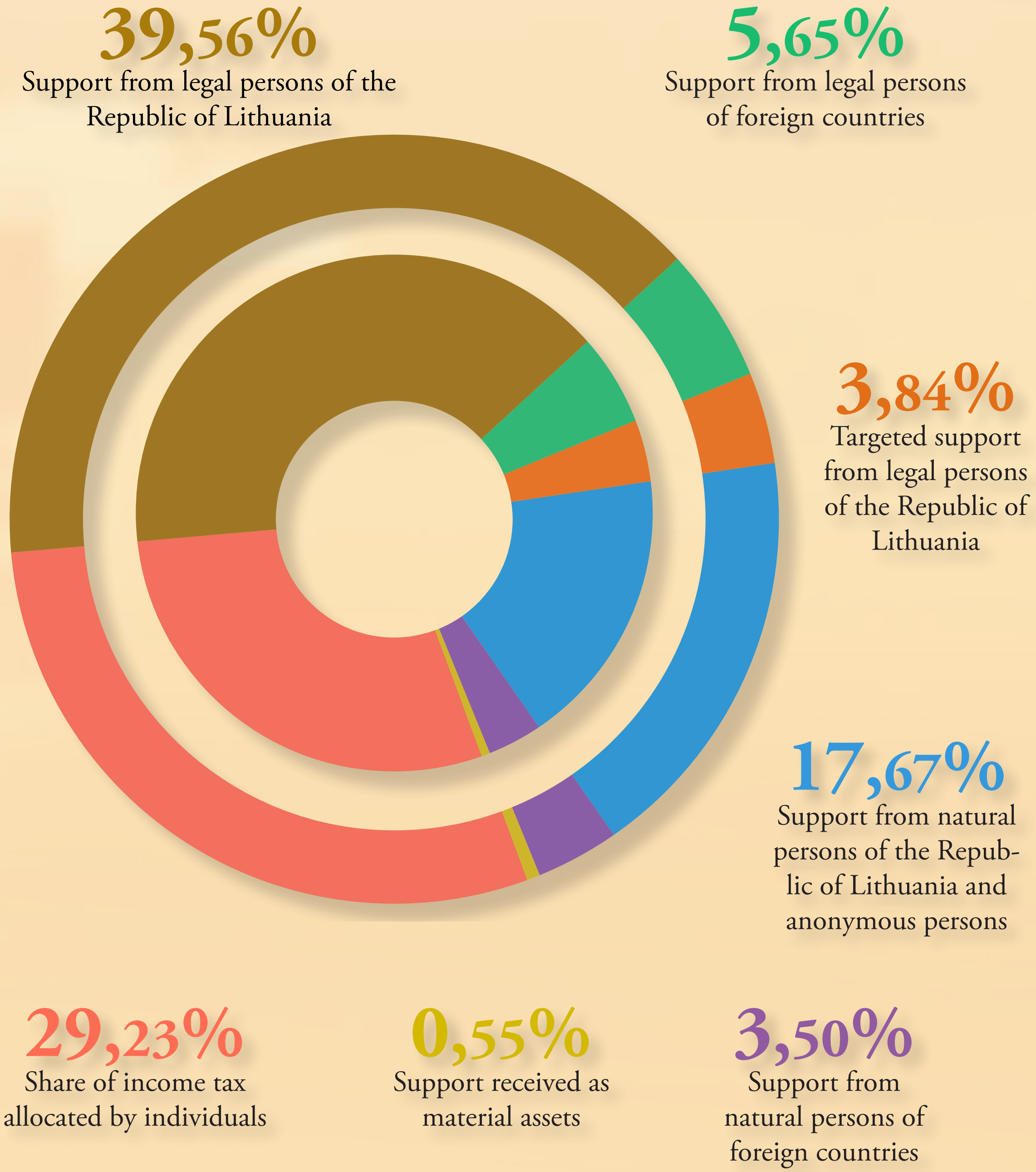
Since its establishment, the Fund has been existing with the help of sponsors and initiatives of volunteers. Volunteers organize support events and concerts, actively contribute to the implementation of the Palankaus vėjo malūnėliai campaign, visit sick children and their families, prepare projects, and edit texts. In 2020, the average number of volunteers was 10.

Diana Petrovienė, a long-term volunteer of the Fund, shared her thoughts on volunteering in the Fund Rugutė.

"I first heard about Rugutė when a friend told me about the magical workshop Palankaus vėjo malūnėliai. She told me about the magic of the workshop, where time explodes like coloured bubbles, where you can discover a different self, and at the same time help children with oncological diseases.

This is how I came to the wonderful Rugutės namai, where everyone who knocks on its door can find a lot of love and warmth. I came and realized that I will stay here for a long time! I am happy to have been a part of the Rugutė family for as long as 11 years. I am proud to be able to contribute to the voyages of the world's bravest little captains through the stormy seas of diseases!

I am often asked why I have been volunteering in this Fund for so long? The answer is simple – because the Fund Rugutė is not just a subject that provides financial support for sick children and their families, buys medicine, finances vital tests, and provides psychological support. It is much more! Rugutė gives love! Rugutė believes in luck! Rugutė is a comprehensive care and eternal friendship! Rugutė is devotion and hope! Rugutė is an eternal journey during which great miracles happen in the lives of the smallest ones!"



SOURCES OF SUPPORT PROVIDED BY THE CHILDHOOD CANCER FUND RUGUTĖ IN 2020

1. Support from legal persons of the Republic of Lithuania: EUR 133,921.00

2. Support from legal persons of foreign countries: EUR 19,138.85

3. Targeted support from legal persons of the Republic of Lithuania: EUR 13,003.95

4. Support from natural persons of the Republic of Lithuania and anonymous persons: EUR 59,822.43

5. Support from natural persons of foreign countries: EUR 11,837.57

6. Support received as material assets: EUR 1,867.90

7. Share of income tax allocated by individuals: EUR 98,966.88

Total support received in 2020: EUR 338,558.58

ACTIVITIES PERFORMED BY THE FUND AND ITS PROJECTS AND INITIATIVES IN 2020

In 2020, the Fund pursued its objectives through the performance of the following activities.

2020 was a truly special year because of COVID-19 that hit the world and brought a lot of chaos and anxiety. At the time when different activities were being slowed down or even postponed in many areas, the children's struggle with oncological diseases had to continue. Uncertainty about the future worried doctors and children's relatives. There were questions about how to protect children and staff from being infected with COVID-19, whether all the necessary medications would really reach the little ones, and whether there would be an opportunity to perform planned tests. At the beginning of the year, there was a severe lack of protective equipment, new rules for hospitalizing children were introduced in hospitals, and patient visiting was restricted. This posed great difficulties for families taking care of their children in hospitals

Although the situation was extremely complicated and difficult, we are happy that we were able to help everyone who contacted us, because that is the main goal of Rugutė: provide help immediately, buy necessary medications, cover the cost of surgeries in foreign clinics, and pay for genetic tests necessary when choosing further treatment. The Fund also provided nursing items that may seem a trifle but are actually very useful. Two small capsules of rinsing liquid can quickly reduce the burning sensation in the mouth and enables a small patient to eat without pain.

Also, it was very important to give charity to the families during the child's treatment, because when a child develops an oncological disease, the family's financial situation gets worse, i.e., income decreases significantly because one of the parents has to take care for the child during the hospitalization period and cannot work for a long time, and the family's costs sky-rocket. Other family members try to spend as much time as possible with the sick child, so in cases where the family lives far from the city where the medical institution is located, a lot of money has to be spent to cover travel expenses. Hospital meals are provided only to the child being treated, so the person taking care of the child must buy his/her own meals. The treatment of oncological diseases with cytostatic drugs often has strong side effects, and the medicines that reduce these side effects are not always reimbursed by the state. Patients' families also have to acquire various nursing equipment at their own expense. Thus, using the support provided by the Fund, the families were able to purchase the necessary nursing equipment and food and cover their travel expenses or other expenses incurred. This has ensured not only a better physical condition of the children but also has improved their emotional, psychological, and spiritual condition which has a huge impact on the success of the treatment and recovery. In 2020, the Fund donated EUR 116,201.39 to families (in cash and material assets).

The need for non-reimbursable medicines existed throughout the year. Medicine is advancing every day, i.e., medicines and medical devices, which cure diseases faster and help to reduce or eliminate the risk of side effects, are constantly being improved. Technologies that are used for the performance of tests and help to identify the causes of diseases (which leads to more effective treatments) more accurately are also being improved. Unfortunately, the amount spent to purchase some of the latest medicines, tests, and medical devices in Lithuania is not reimbursed by the state. Rugutė has been working to help fill this gap for 16 years, i.e., it constantly buys medicines so that onco-haematology specialists treating children could have all the opportunities to prescribe medicines specified in the latest treatment protocols. Taking into account the doctors' requests, the Fund bought medicines for EUR 40,241.14, which enabled the application of innovative oncological disease treatment schemes for the children of Lithuania. There is no doubt that such a treatment leads to higher cancer survival rates and long-term remission.

Sometimes it happens that there is a need to prescribe medicines in a solid and not in liquid (injections) form. Low doses of medicines intended for children in Lithuania are usually unregistered and not reimbursed. In the case of Paula's treatment, the doctors decided that it was not necessary for the girl to spend long days in the hospital ward with a connected drip and she could continue her treatment at home. However, the prescribed medicines Ixoten (50 mg) and Vepesid (50 mg) are not registered in Lithuania. We ordered and bought these medicines for Paula so that she could continue her treatment at home.

For over ten years, Rugutė has been striving to ensure that every child with oncological disease has a long-term central venous catheter, which significantly improves the psychological well-being of the child during the treatment and helps to avoid pain and multiple peripheral catheter insertion procedures. To this day, we remember the story of one small patient, which, undoubtedly, could be told by many other children and their relatives. The patient said, *"When I got sick, every needle-prick seemed like the end of the world. Later, it became more difficult to endure the catheter insertion procedures, as due to all the chemotherapies the veins had become very weak and brittle and were aching. The long-term catheter greatly improved the treatment. The nurses were able to inject medication while I was sleeping, and I did not feel anything. I was able to move completely freely."* Using the support funds (EUR 3,260.71), the Fund bought 14 long-term venous catheters and 190 needles suitable for them.

Every doctor and every parent wants the child on the treatment path to start the day with a smile. In order for a child to be happy, he or she must be rested, i. e, the night should pass quietly and without excruciating pain in the stomach or elsewhere, without fever, and without mouth sores, which is one of the most common side effects of chemotherapy. Lately, we have been making a lot of effort to keep children from experiencing these ailments. The feedback from families that are grateful that their children were able to smile and have the opportunity to continue the treatment without a stuttering stomach makes us admit that such items are not a trifle at all. The Fund provided support of EUR 2,131.51 for the purchase of 23 units of Caphosol mouthwashes. Caphosol is one of the most effective remedies that quickly and effectively reduces damage to the oral mucosa, which facilitates the eating process and encourages to continue the treatment.

Since 2018, the Fund has been helping to purchase special connectors for central venous catheters. Catheter valves and connections are the main ways for the microbes to enter, and special connectors reduce the possibility of catheter infections. 300 special connectors were purchased for the amount of EUR 254.10.

In November 2020, a doctor who has been treating Emilija for ten years contacted the Fund and asked to pay for genetic testing at Roche Pharmholding B.V. Emilija is the first child in Lithuania to be diagnosed with a very rare oncological disease in children, i.e., melanoma. For this reason, the Fund not only paid for the genetic test, but also during the entire treatment period bought medicines that are not on the list of reimbursable medicines. The Fund paid EUR 1,815.00 for the test performed by Roche Pharmholding B.V.

In February 2019, a teenager Aras was diagnosed with a very rare oncological disease, i.e., a liver tumour (hepatoblastoma). In May, doctors decided to urgently send the boy for surgery to the Paediatric Surgery and Urology Centre of Gdansk University Hospital (Klinika Chirurgii i Urologii Dzieci i Młodzieży Gdańskiego Uniwersytetu Medycznego). Due to the urgency of the operation, it was not possible to submit documents regarding the payment of expenses. The fund then covered the costs of the first operation, i.e., EUR 11,536.91. After the recurrence of the disease in 2020, Ainaras had to go to the Paediatric Surgery and Urology Centre of Gdansk University Hospital again, where a tumour growing in the liver was urgently operated on. In that year, the Fund provided support of EUR 6,250.00 to cover the surgery, accommodation, and travel expenses.

In March 2020, the most important thing was masks, respirators, disinfectants, protective goggles, and the ability to order them quickly. When the pandemic hit, we realized that in Lithuania there is a lack of protective equipment for children. Protective equipment intended for adults is not suitable for children. We are glad that we have discovered so much humanity, compassion, and help on this potholed road, because people were not counting their working hours and were helping day and night. Architect Mindaugas Skrupskelis, who lives in China, and Vilijus Samuila, an adviser to the Embassy of the Republic of Lithuania in China, helped to overcome all obstacles and ordered medical equipment.

Children and their families were provided with 1,500 units of children's masks, 1500 units of children's respirators, 8000 units of medical masks, 1000 units of FFP2 respirators, and 30 units of protective goggles. In 2020, the Fund provided support of EUR 7,875.17 for the purchase of equipment necessary during the pandemic. Once again it was good to feel that even the most difficult obstacles can be overcome by joining forces and by supporting each other.

From the very beginning of the fight against an oncological disease, the word you want to hear the most from the doctor's lips is 'remission'. 'Remission' means the end of unpleasant and painful procedures and the ability to return home and have a normal childhood or adolescence. Unfortunately, it often happens that after overcoming the worst disease, i.e., an oncological disease, children experience complications of the treatment, which force them to return to the hospital ward again and again. This is what happened to Laurynas who is sponsored by the Fund. All year round he had been visiting the hospital because of hearing loss, urological problems, etc. The Fund gave Laurynas' family the opportunity to stay at Rugutės namai and provided monthly financial support throughout the year.

Bazilė, like Laurynas, had to overcome not only a serious disease and walk a difficult path of treatment but also fight with the consequences of the treatment. Such a new fight often requires tremendous perseverance, faith, and endless effort. The girl is patiently and gradually trying to overcome all the obstacles and challenges. In June, Bazilė participated in a therapy program at the Dolphin Therapy Centre. After the activities with the friendliest animals in the world, positive psycho-emotional, motor, and sensory changes were observed. Cognitive and socialization skills have improved. We provide a monthly financial support to Bazilė and Laurynas.

Kirilas' journey began in 2013, when a tumour was diagnosed after performing an MRI test of the head area. At that moment, the boy was three years old. Kirilas was treated with chemotherapy and radiation therapy. In 2015, optic nerve atrophy was confirmed. In 2017, a partial tumour removal surgery was performed after which many complications have developed. Since then, the boy has been fed through a gastrostoma. In order to alleviate the family's financial problems, the Fund buys a new gastrostomy package twice a year.

At the beginning of 2020, we met **Jaunius**, a charming boy who we called ‘the Grand Captain’. At the beginning of the year, the boy heard that the disease had returned and he will have to fight again. This time the ocean was much stormier and the wind kept carrying good news farther away. When there was only a distant glimmer of hope left, the storms suddenly calmed down as the new drugs helped to stop the progression of the disease. Hope grew every day as the boy’s big brother Jurgis become a stem cell donor. Jaunius underwent a transplantation of haematopoietic stem cells. Prior to this procedure, the boy underwent high-dose chemotherapy aimed to destroy as many cancer cells as possible in the body and to severely weaken the patient’s immune system so that it does not reject the donor cells and to prevent immunological conflicts between the donor’s cells and the patient’s cells. Jaunius resolutely overcame all the complications and we finally received good news: the disease has receded this time as well. After seeing these children, we would once again like to thank the doctors who were looking for the most effective treatment tactics. Thanks to Jaunius’ parents and his brother Jurgis for their strength and focus. We are grateful for the opportunity to see Jaunius’ smile, to watch the boy grow, change, and spend his days in the safest port of childhood.

In the fall of 2020, we took special care of **Marta**. In mid-summer, the girl was diagnosed with an eye tumour. After the diagnosis and evaluation of the eye tumour, the eye prosthesis was provided and chemotherapy was applied. The treatment was successful, but the girl was often alone in the hospital because her mother was expecting her third child and also had to look after Marta's four-year-old brother at home. The financial situation of the girl's family was extremely difficult, so we tried to take care of Marta as much as we could by buying her clothes and food and transferring financial support to the girl's family. When communicating with Marta, we were especially fascinated by the girl's independence and the pure childish joy she expressed when receiving even the smallest gift. Everyone around her felt her kindness. Marta's laughter and her joyful jumping around the ward made us forget that she was dealing with a serious disease.

The third touching story is about **Alisa**. Alisa teaches people patience and sensitivity and shows what is unconditional friendship, love for other people, earth, and animals. During Alisa's treatment, her mother shared a sensitive message. Learning about the treatment the child will undergo brings many different emotions. The numbing anxiety paints the life in grey and we keep asking the question "Why us?". However, even in this difficult situation, a different approach is possible by asking "What this experience gives us?". The message of Alisa's mother is related with the latter question. There is so much wisdom behind every word she says. We really want to share this message with those who are reading this activity report. Alisa's mother says, *"When I was told that the treatment after the surgery will last 27 weeks it felt like I had flown into space. I don't know... Maybe I'm still there because everything is easier and simpler from there. Laughter sounds more often than cries and there are a lot of hugs and even more love... We are not thinking about the disease (although we know it very well), but about health. We are not thinking about what will come, but about how good it is now. We don't ask "Why us?", but we ask, "What does this teaches us?" And you know... Only 3 weeks of the treatment are left, and one of them is free! On Monday, we received news that we do not have to wait until the end of the treatment for the blood indicators to reach the norms, because they have already been reached. Only three steps left. Of course, there will be things to do next, but this does not make us feel less happy."*

A month after the treatment was over, the girl's family heard the news that the disease had returned. So, our little ballerina was on her second trip. We accompanied the girl during this trip as well. We were quietly admiring the optimism of the family and wishing Alisa to put the shimmering pointe shoes and join ballet classes as soon as possible.

Genetic tests for more targeted and effective treatment of every young patient

In 2016, the Fund launched a long-term project Genetic Tests for More Targeted and Effective Treatment of Every Young Patient.

In autumn of 2016, a scientific discussion took place between Dr. Giedrė Rutkauskienė, the Head of the Paediatric Oncohematology Subdivision of Kaunas Clinics of the Lithuanian University of Health Sciences, and OncoDNA (Belgium) researchers Dr. Jean-François Laes and Dr. Fiona Demol. It was decided that it is most appropriate to perform composite genetic and other molecular tests of oncological solid tumours on children with only high-grade gliomas. Survival prospects for children with this disease are very low, and the treatment applied until now had not been effective. After performing compound and progressive genetic tests, it is expected to offer these children a more precise and specific treatment (depending on the genetic mutations in the tumour) that could help them cope with the disease and achieve remission.

Since August 2016, comprehensive OncoDEEP&TRACE tests (EUR 57,475) have been performed on 19 children diagnosed with extremely malignant tumours of the central nervous system. Tumour biopsy or postoperative specimen samples in paraffin blocks and blood samples were used for the test. The aforementioned samples were sent to the OncoDNA company that is at the Institute of Genetics and Pathology in Belgium. At the Institute, the diagnosis of the tumour was reaffirmed, sequencing of more than 200 oncogenes was performed, and all mutations in them were identified. Also, at the Institute, specific immunohistochemical, methylation, translocation, increment/inclusion, and other tests were performed. Based on the results obtained, a detailed biological report was generated for each patient, and the most appropriate individualized treatment was identified. Based on the report and taking into account the general condition of the patient, individualized chemotherapy or target therapy was prescribed.

In 2020, OncoDEEP&TRACE tests were performed on 1 child. The Fund paid EUR 3,025.00 for these tests.

Rugutės namai

Rugutės namai, which has been operating for twelve years, is one of the cosiest projects. The goal of *Rugutės namai* is to provide free accommodation for children with oncological diseases and their family members if needed. The Fund seeks to ensure that children could have the opportunity to stay in *Rugutės namai*, which is located next to the Vilnius Children's Hospital, and feel like at home, rest after a complicated treatment, and forget the hospital environment. A short rest with the loved ones restores the sense of security and helps the family to preserve the sense of community. Both the relatives of the young patient who come to visit him/her from distant places and the family members who are taking care of the child in the hospital during the day have the opportunity to stay in this house temporarily.

Everyone who stayed at *Rugutės namai* could use/have (free of charge):

- separate bedrooms;
- access to bathroom;
- children's play areas;
- access to kitchen, where you can prepare your own meals;
- washing and drying machines;
- tea, coffee and shelf-stable food;
- small library with a variety of books and other information on oncological diseases;
- internet and cable TV.

In 2020, when isolation became extremely important due to the risk of infection with the new coronavirus (COVID-19), at *Rugutės namai* we accommodated only one family at a time. Jaunius' brother Jurgis waited there until the stem cells were collected. Matas rested there for several weeks after the stem cell transplant because he could not go to his home in another city due to constant changes in his blood indicators. At the end of the year, we invited a Latvian family to stay there. Their daughter Nora underwent stem cell transplantation in Lithuania. Such transplantations are not performed in Latvia. The girl's father became a donor and thus gave her the chance to recover. We kept the girl's father safe in order to avoid any possible outside contacts.

The mother of Armandas, who visited *Rugutės namai*, shared her thoughts about the life in this house, *"Rugutės namai is so warm. It is a place where we feel happy. We feel happy because we can be together. We always find some work to do in our own home and we have our own activities. In Rugutės namai all the members of the family are stuck together. We play games, watch movies, and keep things in order. Even when I am in silence, I feel that I am not alone with the illness and that children have support from more people than their parents. You asked not to thank you but I cannot do that..."*

The mother of Jaunius also spoke very kind words about *Rugutės namai*, *"Do you know what Rugutės namai was for me during Jaunius' illness? It was my home when the real home was too far. A home where I used to see my second son who I haven't seen for weeks. Sometimes even a few hours spent outside of the hospital ward is a lot. After all, sometimes, whenever we could, we just would go for a dinner and would come back to the hospital."*

Other projects of the Fund are also carried out at *Rugutės namai*: preparation for the *Palankaus vėjo malūnėliai* campaign, during which small windmills are produced; Christmas tree decoration with guests from Sweden and celebration of St. Lucy's Day; unpaid blood donation campaign *Padovanok lašelį*. Here, we have conversations with the sponsors of the Fund and all the people who love children and are interested in the activities of the Fund.

The costs of the rent of the premises, utilities, cleaning services, bed linen washing, telephone services, and other amenities provided free of charge in 2020 amounted to EUR 18,226.78.

Bendrauk (Communicate)

Children undergoing oncological treatment have to spend a lot of time in a hospital away from their friends and family members. In order to improve the psychological condition of the sick children, the Fund granted the right to use the mobile Internet free of charge to all children treated in the Paediatric Oncology and Haematology Sector of Kaunas Clinics. In 2020 the Fund provided support of EUR 413.00 to the *Bendrauk* project.

Let's make the dreams of children with malignant tumours come true

Everyone has dreams: those who take the first steps holding the hands of their parents and those whose teenage life passes sitting by the window of a hospital ward. All children undergoing treatment deserve to have their dreams come true, and the days in the hospital would pass more quickly if they could engage in their favourite activities.

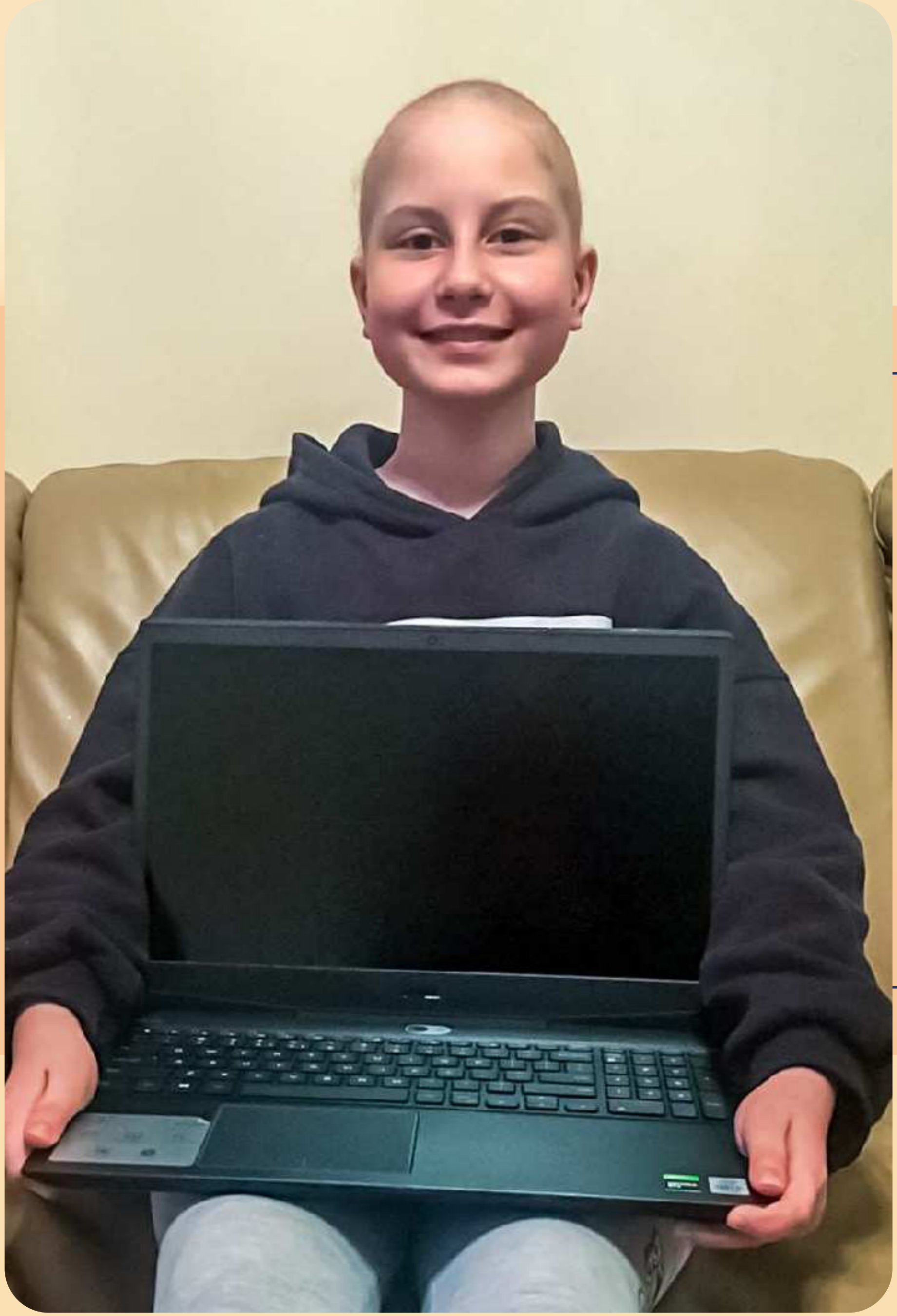
We met Emilia after the girl chose a friend, a bear. She opened the door of the Paediatric Oncohematology Centre last March when she was diagnosed with acute lymphoblastic leukaemia. The oncological disease has become a considerable challenge for the girl, because at the age of six she was also diagnosed with diabetes. During the correspondence regarding the transfer of the bear, we found out about another wish of Emilia. Because of the illness, the girl had to be home-schooled, and therefore she needed a computer. In order for her to be able to find learning material faster, perform assigned tasks, communicate with teachers or friends, or have advise on issues related with studies, a computer was needed.

The threat of COVID-19 silenced the children's laughter in the corridors of the Oncohematology Centre, but the journey through the world of disease continued behind every ward door. After the procedures, the older children read books and communicate with their friends by sending messages. The days are much sadder for little ones who like to play with friends whose destiny is the same. Therefore, as soon as we heard the wish of one little fighter, A. K., i.e., to watch movies and play games for children, we made sure that a new computer will reach the girl as soon as possible.

At the end of the summer, we received a letter from Meda's mother stating *"Recently, my daughter was diagnosed with acute lymphoblastic leukaemia. As horrible as the diagnosis may sound, it is also an opportunity to get to know other children affected by the disease and their parents. This is how we learned about your Fund and the dreams it fulfils. Meda has long been interested in programming and robots. When she was healthy she was able to perform various out-of-school activities and enjoy her hobby, but now she cannot leave the hospital ward and later she will have to stay home. She has long dreamed of a robot with great potential in both design and programming. We love our daughter very much, but we tended to invest more in out-of-school clubs where she could interact with other children. Meda's dream is to have a robot and work with it."* We encouraged Meda to pursue her dreams and we were happy to be able to fulfil her dream.

In the fall, a letter from Deimantas' mother reached us. The mother said that in 2016 her son began his fight against a malignant brain tumour (medulloblastoma) for the first time. He won the fight, and until August of this year Deimantas had been living a normal teenage life. Unfortunately, for unexplained reasons, the disease, which has been gone for a while, came back again this year and forced 16-year-old Deimantas to join new battles. When we heard Deimantas' request to donate new glasses, we were touched and wished for him to have fun moments of distraction in the world of books, movies, or games, and therefore we tried to fulfil this dream as soon as possible.

Fifteen-year-old Vladislav was timid when he told us that he began the treatment of acute lymphoblastic leukaemia in February. The first months of active chemotherapy were very difficult, so he had to stay at the hospital from 27 February until 1 June. By the time Vladislav contacted the Fund, the treatment was a bit milder, and he had to visit the hospital only to inject medicines and perform tests. His energy taken by active treatment was returning very slowly. Therefore, when we heard the request to help buy an indoor bike trainer that could strengthen the leg muscles and help the boy run again and play football with friends, we did not hesitate. The boy also asked for help in purchasing a comfortable chair which he could use when participating in the educational process. Vladislav cannot go to school, so he studies remotely. For the charming teenager, we wished to climb as little steep hills and slopes throughout the treatment as possible.



Every day, the Fund Rugutė gives love and compassion and takes care of all the children fighting against oncological diseases. So, we want to share another story about a fulfilled wish, which put a smile on a child's face. At the end of summer we received a letter from a father of a charming ten-year-old girl named Skaistė. Due to the disease (acute lymphoblastic leukaemia) she had to be home-schooled, so the girl desperately needed a computer. With a computer she would be able to find learning material faster, perform assigned tasks, communicate with teachers, or have advise on issues related with studies. Thanks to the sponsors of the Fund, we managed to give the girl the opportunity to study more comfortably, to be more curious, to find answers to the questions that concerned her and thus, improve her skills every day even if she was spending time in the hospital ward or at home.

In 2020, the Fund provided support of EUR 5,486.14 to make these dreams come true.

Aquarium for children in the hospital

In 2012, the idea of Eugenijus Mačiukas, the father of a boy with an oncological disease, to donate two aquariums to children undergoing treatment at the Paediatric Clinic of Lithuanian University of Health Sciences was implemented. Professionally equipped large and beautiful aquariums with live fish and special vegetation not only provide a feeling of comfort to the hospital premises but also have a psychotherapeutic effect on young patients, i.e., help them calm down, relieve tension and fear, and forget pain and strengthen their spirit. Better emotional well-being of children ensures the effectiveness of treatment of the disease and faster healing processes. A pleasant environment that evokes good emotions is especially important for children whose hospitalization lasts for many months.

In 2020, the Fund provided support of EUR 219.35 for the renovation and maintenance of aquariums.

Palliative care. Nursing at home

For ten years now, the Fund has been also focusing on palliative childcare. We believe it is necessary to assess the needs of a child who is in need of palliative care and the needs of his/her relatives and give them the opportunity to choose where to spend this stage of the disease, i.e., at home or in the hospital.

Support in the form of medical equipment and other items

In close cooperation with medical institutions treating children with oncological diseases, the Fund helps to acquire not only the necessary medical/nursing items, but also medical equipment intended for more targeted and effective treatment of the young patients.

We always say that the most accurate tests and the best possible medicines are key to the successful treatment of children. But these are only part of success. Many details that are not always noticeable are also of great importance. For example, all procedures will be performed more accurately and faster only in well-lit treatment rooms. For this reason, the Fund helped to purchase a lamp (EUR 1,331.00) for the treatment room.

During the treatment of an oncological disease, the hospital becomes a temporary shelter which can be left just for a short time in order to go home. In the hospital wards, it is not all about medicine, but also about a regular routine. For instance, children are watching TV and playing games, and their mothers are running to the kitchen to make a tasty meal which may be the only source of strength that day. Therefore, as soon as we heard that the broken hot plate needed to be replaced and that in one of the wards it was very silent because of a broken TV, we hurried to solve the problems. The Fund paid EUR 359.98 for the hot plate and TV.

When autumn came, even the hospital wards were cold and all you wanted is to wrap yourself in a soft blanket and have a cup of warm and fragrant tea. After all, the hospital ward has become a home, sometimes for a week and sometimes for several months. Therefore, wishing that the children and their families could enjoy fragrant tea aromas, we provided new kettles. The Fund paid EUR 141.59 for the kettles.

It is said that the sweetest thing in the world is sleep. It is also said that children recover during sleep. We wished them to have sweet dreams and a speedy recovery, and therefore we provided new soft pillows for the renovated wards of the Paediatric Oncohematology Centre, where we also hid dozens of colourful dreams. The Fund paid EUR 216.29 for the pillows.

When COVID-19 spread in Lithuania in the spring of 2020, there was a lack of disinfectant, soap, and other protective equipment in every hospital ward, including the Paediatric Oncohematology Centre. The safety of children is of paramount importance to us. So, the centre where these children were treated was quickly provided with liquid disinfectants, antibacterial soaps, respirators, and masks. The total price of the equipment was EUR 5,217.34.

When cooperating with the Paediatric Oncohematology Sector of Kaunas Clinics, the Fund bought 3 non-contact thermometers which were intended to facilitate the monitoring of children’s condition. The cost for these thermometers amounted to EUR 158.00.

During the treatment of oncological diseases, aside from timely provision of targeted and effective treatment, improving the skills of the nurses (participating in international conferences and meetings) is also important. For this purpose, the Fund provided EUR 2,000.00 in support to the Lithuanian Society of Paediatric Oncohematology Specialists.

The total amount of support provided in 2020 is EUR 10,737.20.

Improvement of the household of children’s treatment centres

The emotional and psychological well-being of the children is extremely important during the treatment of oncological diseases. The Fund Rugutė was happy to contribute to the renovation of the playroom and psychology service rooms, and to the creation of festive Christmas mood and bought various targeted equipment for EUR 2,009.48 intended to improve the children’s emotional condition.

Before Christmas, some children spend their days in hospital wards where they are constantly receiving “drops of life”. The children sit at a small table where they celebrate Christmas Eve and Christmas. We wanted for the children to be happy during the waiting period in December, and therefore we bought a wide variety of dwarfs that brought colours, smiles, and joy to the wards and corridors. We were really happy that we were able to create a wonderful Christmas fairy tale: every child wanted to hug the dwarf, say “hi” to him, and tell him the most secret dreams. After all, nothing is more important than knowing that the holidays will come no matter where we are.

Padovanok lašelį (Give a droplet)

In 2020, the *Padovanok lašelį* campaign, which had been organized by the Fund for thirteen years, did not take place due to restrictions. We encouraged well-known donors to go to the National Blood Centre and donate blood safely on its premises. Since its establishment, the Fund has been fostering the idea of unpaid blood donation. The friendship with the National Blood Centre began at the very beginning of the operation of the Childhood Cancer Fund Rugutė, i.e., on 15 September 2005. The first blood donation campaign took place on that day, and in 2008, when Rugutės namai was established, we invited people to donate blood twice a year, i. e. at the beginning of summer and at the end of autumn when Rugutė celebrates its birthday. It is estimated that one blood donor can save the lives of 3 people. So, together we facilitated the recovery of at least two thousand people during those years. Blood transfusions are often needed to save the life of a person who has suffered a serious health problem or serious trauma, and the blood of donors is the most meaningful gift for such a person. We have no doubt that we will continue this project when the restrictions applied due to the pandemic will be lifted.

INITIATIVES OF OTHER COUNTRIES INTENDED TO HELP LITHUANIAN CHILDREN WITH ONCOLOGICAL DISEASES

Visit of dwarfs

This extraordinary history of friendship began in 2007, when Bengt Nilson, who lives in Sweden, invited Lithuanian children with oncological diseases to come to the Joy Festival organized by him. Since then, every year, in the middle of December, a group of cheerful dwarfs (Stefan Espersson, Anita Larsson, Ieva Sturesson) arrives in Lithuania, and two students (different each time) are invited to distribute gifts and give joy to the children. During the visit, going from one hospital ward to another, dwarfs from Sweden not only hand out presents to the young patients of Children's Hospital of Kaunas Clinics and Vilnius University Hospital Santaros Klinikos' Branch Children's Oncohematology Centre, but also perform other activities, i.e., juggle, sing in Swedish, dance, and wish a peaceful holiday. Meetings with dwarfs leave indelible impressions on the children's hearts.

This is also confirmed by Domantas who in his letter says,
"You are the only child we visit every year," said the eldest dwarf Anita, who visited me again this morning. I'm trying to count how many times we hugged. Nine, ten or more? The heart is filled with joy and excitement every time we meet. For me, the waiting of the holidays begins after their visit because they bring that long-awaited Christmas spirit and Christmas mood. While drinking tea, we tell each other how our year has passed. Anita shared memories of our first meetings about how I always asked to give Santa my baked cookies. Thanks to Anita, Stefan, Ieva, and two other dwarfs for the meeting. See you next year! Happy holidays to everyone!"

Unfortunately, the pandemic that has hit the world this year has taken away the opportunity to hug our beloved Dwarfs, sing Swedish songs, and play games. Nevertheless, our loyal friends Stefan, Anita, and Ieva did not give up and were telling stories to everyone about the previous meetings and raised funds for children who are undergoing difficult treatments in Lithuania. The funds raised were transferred in early 2021. We believe in the continuity of this project after the end of the pandemic and we are very much looking forward to seeing Stefan, Anita, and Ieva in Lithuania again.

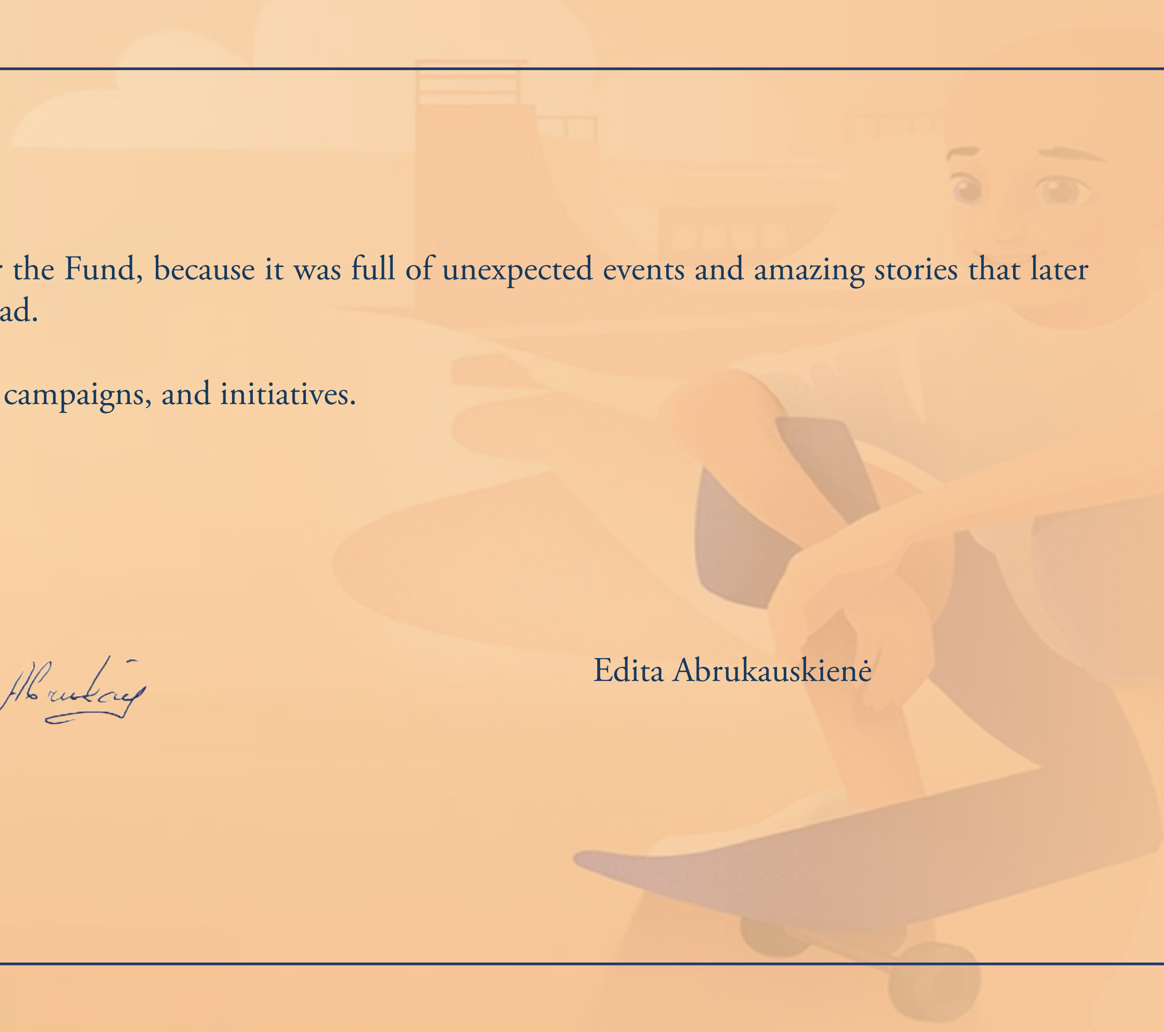
Onco-Olympics 2020 sports games

Every two years, friends of the Fund Rugutė, i.e., Fundacja Spełnionych Marzeń (Fulfilled Dreams Foundation), an organisation operating in Poland, organises international football games Onco-Olympics for children with oncological diseases. Fundacja Spełnionych Marzeń says this about the games, *"The main goal of the Onco-Olympics is to increase the self-confidence of children with oncological disease, especially of those children who have suffered from long-term health problems due to the disease which are limiting their ability to participate in active group activities in their environment. Another important goal of the Onco-Olympics is to promote active statements about the provision of support for children with oncological diseases and their families, and thus overcome stereotypes and raise public awareness of oncological diseases."*

The team of the Fund Rugutė represented Lithuania five times in the Onco-Olympics (in 2010, 2012, 2014, 2016 and 2018), and in 2019 we defended the honour of Lithuania for the first time in the football championship Onco-Liga. Athletes competed in swimming, table tennis, archery, and athletics competitions and returned home with medals. Some also brought medals from two different competitions! The Lithuanian anthem was played more than once when the winners climbed the highest step of the podium.

However, the most important thing is not the medals or the opportunity for children to test their athletic skills. These games are a great opportunity to meet the children from other countries who had the same experiences. New acquaintances, emotions experienced during the competitions, time spent together, adventures, and the feeling of community that is present throughout the games give both the children and their family members confidence to go forward.

In 2020, we received painful news of the loss of Tomasz Osuch, the head of the fund and an extremely passionate person who was able to rally many people to help children. Though, we have already received confirmation from the fund that this meaningful friendship project will continue.



We can state that 2020 was undoubtedly one of the most difficult years for the Fund, because it was full of unexpected events and amazing stories that later make you stop, look back, and remember the experience and feelings you had.

In 2020, the Fund allocated EUR 149,075.87 to charity, support, projects, campaigns, and initiatives.

Director of the Childhood Cancer Fund Rugutė
12 May 2021

Edita Abrukauskienė