

kick cancer



**I'm too small to
cure, are you too
big to care?**

A few key metrics

1.8 million euros raised over one year – and 6 million during the first four years

5 new research projects financed for 725 000 euros

1100 runners participating in RUN TO KICK and 10 000 donors who supported KickCancer

More than 225 mentions in the press

13 people contributing to KickCancer's success as employees, freelancers or volunteers

2 kicking ambassadors: Angèle and Niels Destadsbader

18 000 éclairs sold to give cancer a taste of its own medicine

5 contributions to European public consultations

Dear KickCancer friends,

As KickCancer celebrates its fifth birthday, we are issuing this annual report.

5 years, that's quite something! "Round" birthdays are great moments to reflect and look back in time and let's admit it, we are not bound to be modest: we are very proud of you, the best supporters ever! We went back to our first reports, where we explained the first stepstones of what defines our vision, and we are now enthusiastically adding new tricks up our sleeves.

We have been so far blessed with a stellar growth despite a rather... chaotic environment with two out of five years that swung from lockdown, confinement to a return to social life... but here at KickCancer, we have a sweet tooth for challenges and take some pride in being creative.

In 2021, we were ho-so-excited to see you come back in flesh, shorts and sneakers to run with us for RUN TO KICK and we were extremely thankful to see our fundraiser for FIGHT KIDS CANCER grow with more than 100 000, from 610 000 to 725 000 €... all of which were invested in our second European call for projects!

As a result, together with Imagine for Margo (France), the Kribskrank Kanner Fondatioun (Luxembourg) and FIAGOP (Italy), we have already jointly invested **6,5 million euros in 3 clinical trials and 8 translational research projects since 2020**. For our third edition, we see the scientific community's rising interest in our call as we have received 66 letters of intent.

When this report will come out of the printer, we will have selected new research projects for a fluffy amount of 4 million euros — the projects for which you will run next September at RUN TO KICK (register now!). As we are coming out of the covid era, hopefully, we have set a very ambitious target that we intend to reach thanks to you: a KickCancer's share of 1 million euro in the call! But we know **you can do it for the kids!**

Meanwhile, in 2021, our **Patients' Committee** became a reality with a class of 14 expert patients

who completed a thorough training and graduated in December 2021. They are now eager to start contributing to research by instilling the patients' perspective into the projects as the best research must meet patients' needs.

We also concluded a structural agreement with the **Belgian Society for Paediatric Haemato-Oncology** (BSPHO), whereby not only do we undertake to finance their office costs to sustain their efficiency, but we also agreed to organise bi-yearly meetings to identify the (mostly clinical) research projects that KickCancer will finance. As a result, end of 2021, we jointly identified 4 projects for a total amount of 740 000 € that we shall start financing in 2022.

In 2022, we are determined to make our first serious steps on the Belgian policy scene, with **our first Patients' conference** about the reimbursement of drugs in paediatric oncology, for which we want to find sustainable and structural solutions to ensure fair and equitable access to the best drugs for all patients and to reduce the administrative workload for doctors and social workers in hospitals.

We have also launched several **KickCancer's projects to empower newly diagnosed patients**, with the generous assistance of our new patient experts.

Finally, we have a **serious European agenda to attend to...** with several key regulations that will be discussed in the European Parliament in December. We are determined to make sure that those revised regulations will contribute to accelerate and facilitate innovation for young patients with cancer!

I hope these lines will have convinced that you are more than ever a real partner in our growth, and we hope to see you around for the rest of 2022. Stay around!

Delphine Heenen
Kicker-in-Chief



Our mission

We want to cure every child's cancer. Find new treatments, improve existing ones, and kick children's cancer to send it far, far away forever and may it never come back!

Paediatric cancer is the 1st cause of death by disease for children above 1 year of age

All paediatric cancers are rare, but some are very rare and receive very little scientific attention even if some of them have a very poor cure rate (below 50%). The situation will only improve if we finance more research about those high-risk cancers.

6.000 deaths in Europe / year

2/3 survivors suffer from long-term effects

Nowadays, anti-cancer treatments are heavy and leave survivors with severe long-term sequelae. Survivors represent about half a million people in Europe today. We must make sure that those long-term sequelae are either prevented or properly identified and treated or prevented.

Cognitive dysfunction (blindness, hearing loss)

Knee or hip replacement (major joints)

Amputation (foot, leg, hand...)

Organ removal (kidneys)

Coronary or artery disease

Cardiac failure

Secondary cancers

Post-traumatic stress disorders

Every kid cancer is a rare disease

There are about 16 main types of paediatric cancers (leukaemia, brain and spinal cord tumours, neuroblastoma, lymphoma, rhabdomyosarcoma, osteosarcoma...). Each of those is divided into several sub-groups. In total, it adds up to about 60 different paediatric malignancies and each of them requires a specific scientific attention.

35.000 new cases in Europe / year

Innovation is lagging for children, and survival rate is stagnating

Interestingly, this happened while significant progress occurred in adult oncology. And why not for children?

150 new drugs for adults vs. 9 only for children since 2007

Only 1 in 10 children who runs out of treatment options has access to an innovative clinical trial

When standard treatments no longer work, it is common practice to offer a patient running out of therapeutic options the opportunity to participate in a clinical trial — even if the efficacy of the treatment is not demonstrated yet. In paediatrics, this option is only an exception. We need more funds for academic research and a more favourable regulatory context so that new drugs can be discovered in paediatric oncology and that more clinical trials open for the benefit of children with cancer.

Prevention and early detection are not valuable strategies for children today

We do not know the causes of childhood cancer. As a result, we have no tool to prevent children from getting cancer. Only a small portion of children who have been diagnosed with cancer (5 to 8%) have a known genetic predisposition to develop cancers. To those children, we need to offer regular check-ups to allow an early-stage detection of any new upcoming cancer. For all the other children, we must finance research on the causes of paediatric cancer.

Adolescents and Young Adults (AYAs) need proper care facilities

Being a “big child” in a paediatric ward or a “young buddy” in a cancer centre: this is how adolescents and young adults feel when they are diagnosed with cancer: they feel like they do not belong to where they are.

It is not “just” a question of recognition: being treated in age-appropriate facilities has a direct impact on the quality of care, the patient's ability to trust its treatment and even access to adapted or innovative treatments.

We must help AYAs improve the quality of care and access to research too.

+/- 60 000 new AYA cases in Europe/year

1. Activities report

GLOSSARY

CAR-T cells

Treatment that boosts the natural ability of the patient's immune cells (the T cells) to fight cancer. In this treatment, immune cells are taken from the tumour. Those that are most active against cancer are either selected or genetically modified in the lab to better attack the cancer cells, grown in large batches, and reinjected into the patient's body. T-cell transfer therapy may also be called adoptive cell therapy, adoptive immunotherapy, or immune cell therapy.

Diffuse intrinsic pontic gliomas (or DIPG)

A type of brain tumour for which there is currently no cure. Research for these brain tumours is direly needed.

Epigenetics

Epigenetics is the science which explains gene coding: it allows us to understand why cells with the same genetic code have different functions inside someone's body. Think about a very long book from which some words would be highlighted in different colours to create several alternative plots.

Ewing's sarcoma

Ewing's sarcoma is a malignant bone tumour that occurs mostly in young patients (80% of the patients are under 20 years old).

Genetic mutation

Alteration in the genetic material (the genome) of the cell that is more or less permanent and that can be passed on to future cells during cell reproduction.

High debit sequencing

Technologies that sequence DNA and RNA in a rapid and cost-effective way.

High-grade glioma (HGG)

HGG is one of the most common malignant childhood tumours of the central nervous system (brain tumour).

Immune checkpoint inhibition

Our immune system is capable of detecting the difference between "foreign" cells and "normal" cells. This capability enables the white blood cells to attack foreign cells while sparing the normal ones. In order to start an immune response, certain checkpoints located on the white blood cells must be activated but cancer cells, which are produced by our own body, are able to prevent the activation of those checkpoints. This is why the white blood cells do not attack the cancer cells. Checkpoint inhibitors can inhibit a specific checkpoint. When the activation of that checkpoint is inhibited, the white blood cells can attack the cancer cells and cause their death.

Immunotherapy

Immunotherapy is a type of cancer treatment that helps your immune system fight cancer. The immune system helps the body fight infections and other diseases. It is made up of white blood cells and organs and tissues of the lymph system.

There are several types of immunotherapies, including **immune checkpoint inhibitors*** and **CAR-T cells***.

Late phase clinical trial

Clinical trial where standard treatment (or the treatment currently recognised as the best for this indication) is compared with a tweaked treatment. Typically, these clinical trials are proposed to patients upon diagnosis.

Leukaemia

Leukaemia is a broad term for cancers of the blood cells. The type of leukaemia depends on the type of blood cell that becomes cancer and whether it grows quickly or slowly.

Paediatric forms of leukaemia include acute lymphoblastic leukaemia and acute myeloblastic leukaemia.

Liquid biopsy

The purpose of the "liquid biopsy" technique is to collect cancer cells in the blood as opposed to a sample taken by surgery.

Lymphoma

Cancer of the lymphatic system (which plays a key role in our immune system). The two main types are Hodgkin lymphoma and Non-Hodgkin lymphoma (NHL).

Medulloblastoma

Medulloblastoma is a high-risk brain cancer in children. It is the most common brain cancer (20% of brain and spinal cord tumors).

Metronomic chemotherapies

Treatment in which low doses of chemotherapy are administered continuously or frequently, on a regular schedule (for example, daily or weekly), usually over a long period of time. Metronomic chemotherapy has less severe side effects than standard chemotherapy, can improve life expectancy, and ensures a better quality of life during treatment.

Neuroblastoma

Neuroblastoma is a tumour that mainly occurs in young children and derives from nerve cells located in the abdomen or next to the spine.

Osteosarcoma

A cancer of the bone that usually affects the large bones of the arm or leg. Osteosarcoma mainly affects adolescents and young adults.

Platform trial

A "platform trial" is a clinical trial with a single master protocol in which multiple treatments are evaluated simultaneously.

Adaptive platform designs offer flexible features such as dropping treatments for futility (lack of efficiency), declaring one or more treatments superior, or adding new treatments to be tested during the course of a trial.

Rhabdoid tumour

Rare and fast-growing paediatric cancer that usually forms in the kidney or central nervous system (the brain and spinal cord) but can also form in soft tissues in other areas of the body.

1.1. Research Projects

KickCancer finances 15 research projects in the hope of improving treatments for children with cancer.

1.1.1. NEW RESEARCH PROJECTS

FIGHT KIDS CANCER projects

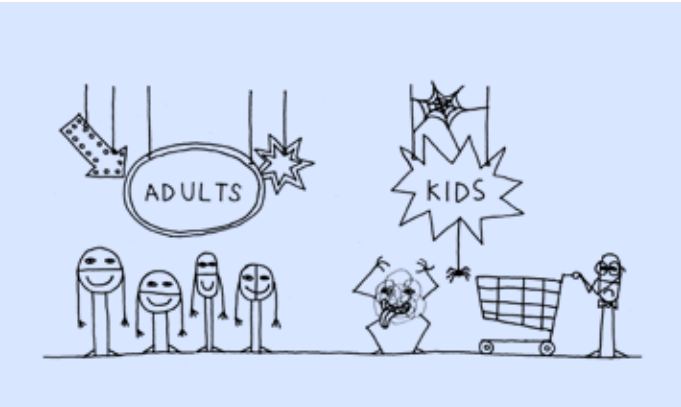
The projects described in this section have been selected by independent experts as part of the FIGHT KIDS CANCER European call for projects. The funded amount indicated per project is the total cost of this project, which is supported jointly by Imagine for Margo (France), the Foundatioun Kriibskrank Kanner (Luxembourg), FIAGOP (Italy) and KickCancer.

A global clinical trial to get rid of lymphoma

Despite intensive treatments, young patients with non-Hodgkin's B-cell **lymphoma** (LNHB) who relapse or do not respond to treatments (refractory disease) are below 30%.

Many new treatments have been developed for this type of lymphomas in adults. It is now necessary to identify those that will be most effective in young patients and this, despite the hurdle of the small patients' population that can be recruited for clinical trials. This is the objective of the "Glo-BNHL" clinical trial, a worldwide study which aims at evaluating — alone or in combination with existing therapies - the toxicity and efficacy of the most promising new treatments for children to increase the cure rate in these patients. This programme will create a unique global **platform** for early clinical **trials** for relapsed and refractory LNHB in at least 30 centres in a dozen countries in Europe, North America, Australia, and New Zealand with the possibility of further expansion. Participants will be divided into 3 treatment arms, each proposing a different new agent.

Financed: 1 161 000 €
Duration: 36 months
Countries: UK, France, Italy, Germany, Netherlands, USA, Canada, Australia, New Zealand
Diseases: Lymphoma
Status: Ongoing since 2022



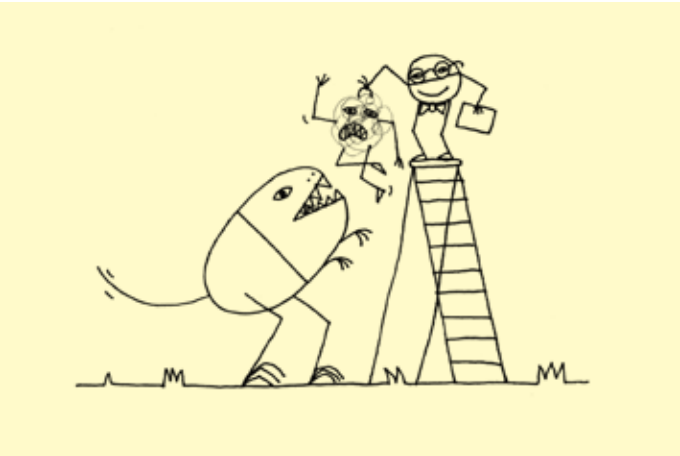
A clinical trial to break new ground in sarcoma treatment

The standard treatment for **Ewing's sarcoma** includes chemotherapy and local treatment with radiotherapy or surgery when possible. Despite this heavy treatment, the chances of survival for these young patients, when their disease is metastatic at diagnosis, amount to 30% only and half of the relapses occur already while in treatment.

Therefore, the "INTER-EWING-1" clinical trial will study whether adding a new agent called "regorafenib" improves the effectiveness of the standard chemotherapy. The clinical trial will be proposed to patients immediately upon diagnosis.

Regorafenib is s a drug from the class of enzyme inhibitors; enzymes play a role in many cellular functions, such as cell growth or division. By inhibiting this enzyme, we are hoping to block the growth of cancer cells and thus improve the treatment for young patients.

Financed: 784 000 €
Duration: 36 months
Countries: France, UK, Italy, Spain and Netherlands
Diseases: Sarcoma
Status: Ongoing since 2022



1.1. Research Projects

A winning combo to exterminate medulloblastoma

Today, treatments cause significant long-term side effects, and the rate of incurable relapse remains very high.

The translational research project “CARBEMED” aims at identifying a highly innovative treatment strategy that would combine two **immunotherapy** techniques:

- A new drug from the class of “**checkpoint inhibitors**”, a technique that prevents cancer cells from going unnoticed (like normal healthy cells) by white blood cells;
- A **CAR-T cell therapy** treatment that reinforces the natural ability of the immune system to fight cancer.

Many other childhood and adult cancers present mechanisms of action that are similar to **medulloblastoma**. If successful, this combination could therefore benefit these patients as well.

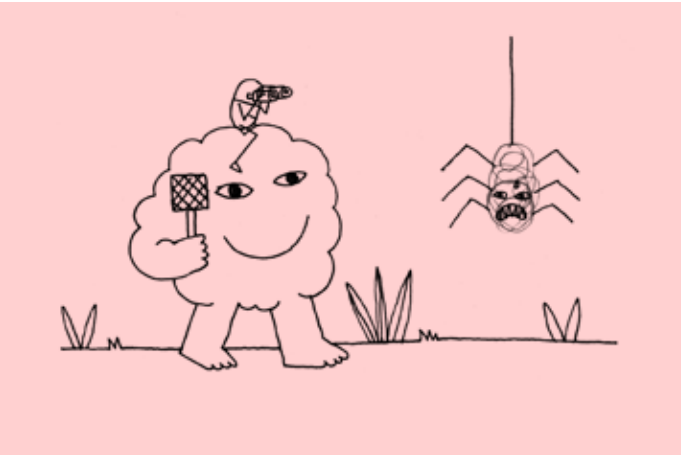
Financed: 499 000 €

Duration: 36 months

Country: United Kingdom

Disease: Medulloblastoma

Status: Opening soon



Overcoming treatment resistance in neuroblastoma

The survival rate of children with high-risk neuroblastoma whose tumour has an alteration in the “ALK” gene are very low.

In these children the first-line treatment now includes, in addition to chemotherapy and local treatment, targeted therapy. This targeted therapy has the effect of preventing cell division and inhibiting the growth of cancer cells. However, in 12 to 15% of these patients this first-line treatment does not work.

The translational research project “COMBALK” aims at improving our understanding of the role of the ALK protein and other factors in the development of neuroblastoma in children and at identifying the mechanisms of resistance to this ALK inhibitor. It will then aim at identifying possible new treatments and combinations to overcome those resistances.

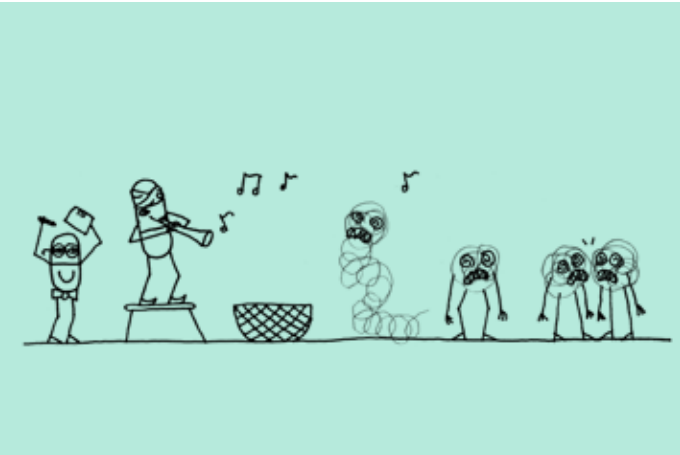
Financed: 500 000 €

Duration: 24 months

Countries: UK, France

Diseases: Neuroblastoma

Status: Ongoing since 2022



Improving our understanding of the mechanisms of resistance in neuroblastoma

Despite intensive treatment, more than one in two patients relapse after frontline treatment and the chances of survival for these patients are below 10%.

The international collaborative project “BEACON-BIO” aims at (1) studying the impact of genetic and **epigenetic** factors in relapse and resistance and (2) identifying new combinations of molecules in the hope that they will be more efficient.

To this end, this project will attempt to allocate patients into risk groups defined on the basis of their molecular specificities (or biomarkers) and treatment resistance.

These combinations will then be evaluated in the upcoming European platform trial in relapsed and refractory **neuroblastoma**, which the European collaborative research groups are currently setting up.

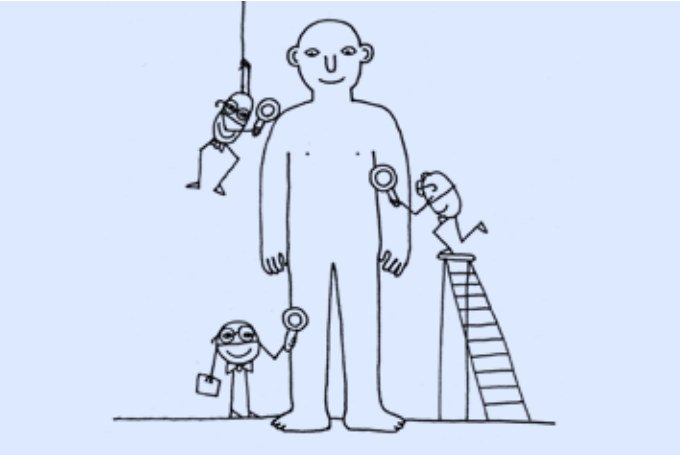
Financed: 500 000 €

Duration: 24 months

Countries: Spain, France, United Kingdom

Diseases: Neuroblastoma

Status: Ongoing since 2022



1.1.2. ONGOING PROJECTS

FIGHT KIDS CANCER projects

A very innovative clinical trial for brain tumours

Standard treatment for **high-grade glioma (HGG)** consists of surgery when possible and radiotherapy in all cases. Chemotherapy or other drugs in clinical trials may be added during and/or after radiotherapy depending on HGG subtype. In most cases, despite this heavy cocktail, the cancer comes back — in some subtypes, 100% children relapse.

This is why this study, called “AsiDNA Children”, is trying a new drug: AsiDNA in association with radiotherapy in children and adolescents with recurrent HGG that have previously been treated with radiotherapy. AsiDNA is a new kind of drug that could be effective to treat HGG because its mechanism of action increases the vulnerability of tumour cells to radiotherapy without attacking other healthy parts of the body.

The hypothesis of the “AsiDNA Children” study is that, in children and adolescents with recurrent previously irradiated HGG, this drug in association with radiotherapy will prolong survival and improve patients’ quality of life.

In 2021, 14 European sites were selected to include patients. The trial is now open in France and will soon begin recruiting its first patients. The opening of the trial in Italy, the Netherlands and Germany is planned for the second half of 2022.

Financed: 580 000€

Duration: 1 year

Countries: France, Italy, the Netherlands and Germany

Disease: High grade glioma

Status: Ongoing since 2021



1.1. Research Projects

Cutting edge technology to crack an aggressive brain tumour

The high-grade neuroepithelial tumour with a BCOR-alteration (CNS HGNET-BCOR) has distinct molecular characteristics, is highly aggressive and has a poor clinical prognosis. To date we do not know the biological processes that drive this tumour type and no effective treatments exist.

The collaborative project POBCORN aims at in-depth investigation of CNS HGNET-BCOR biology with cutting-edge molecular technologies. The tumour samples will be studied with different techniques, including **genetic sequencing, epigenetic** and transcriptomic (how proteins are created) analysis.

- POBCORN has two objectives:
- identify which events lead to tumour growth as well as potential therapeutic targets
 - test in a pre-clinical setting several identified drugs which show potential promises to improve the treatment for those children with a poor prognosis.

It also aims at providing first translational guidance on how to treat CNS HGNET-BCOR patients in future clinical trials. The BCOR alteration is also found in other tumours such as glioblastoma, medulloblastoma... Those findings could also benefit those latter patients.

Since its official launch in May 2021, the project gathered a cohort of more than 200 patients and secure their genetic materials. The genetic sequencing as well as **epigenetic** and transcriptomic analysis are currently ongoing.

Financed: 498 000€
Duration: 2 years
Countries: Austria and Germany
Disease: Brain tumour
Status: Ongoing since end of 2021



Beating relapses and resistance to treatment in blood cancer (AML)

Many children with acute myeloid **leukaemia** (AML) relapse (35-45%) and the overall survival chances remain low (60-75%).

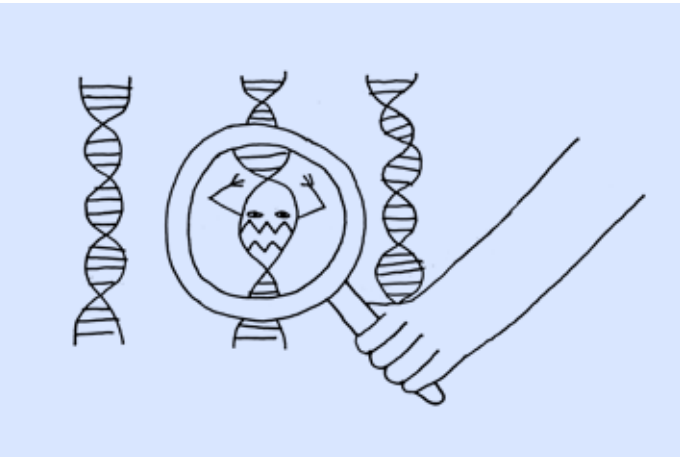
Genetic abnormalities carried by AML cells are responsible for the relapse and the occurrence of the mechanisms of resistance to treatment. We now know that the cells from the microenvironment of the bone marrow play a role in “maintaining” AML cells and in mechanisms of resistance to treatment.

This project “ALARM3” focuses on AML cells at relapse and the understanding of their interactions with the bone marrow microenvironment.

- The project will deliver on multiple approaches, which will lead to:
- A genomic characterisation at first diagnosis and relapse of AML and bone marrow cells
 - A better identification of the patients most at risk of relapse
 - The identification of new targeted molecules to treat children with AML
 - A study of the evolution of drug sensitivity between initial diagnosis and relapse with the ultimate goal to improve the patients’ outcome through a personalisation of the therapeutic strategies.

For administrative reasons, the project only started end of 2021. Therefore, the research team will communicate its first progress report end of 2022.

Financed: 499 000€
Duration: 2 years
Country: France (centres of Paris, Lyon and Marseille)
Disease: Acute myeloid leukaemia
Status: Ongoing since the end of 2021



Epigenetics for rhabdoid tumours

Survival rate for the patients with a **rhabdoid tumour** is under 50% and those surviving will have to go on with their life with oftentimes severe long-term side effects caused by their treatment.

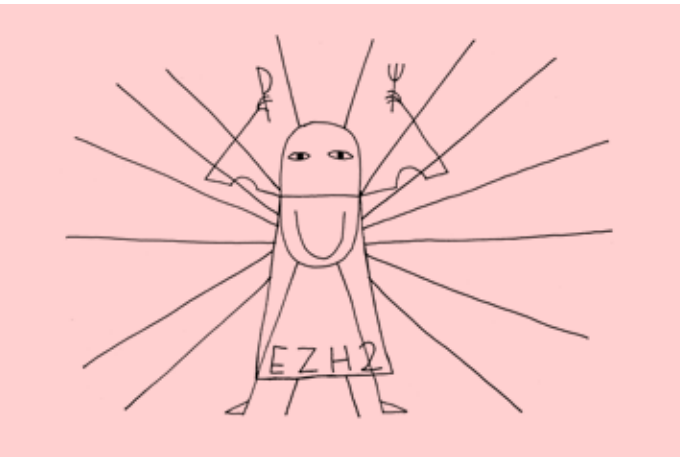
These tumours are characterised by the loss of one unique gene, called SMARCB1. Since there is **no other gene defect**, SMARCB1 constitutes the only direct targetable gene in this disease. Because of its highly **epi-genetic** character, one major field of research for further therapeutic development concerns drugs that do target epigenetic actors.

The “EpiRT” project will focus on the role of one **epi-genetic** drug in rhabdoid tumours, inhibiting the **epigenetic** protein “EZH2”, which inhibition has shown some preliminary effects in the clinics.

The project has two aims: improve our understanding of (i) the resistance mechanisms by analysing them at the cell level, how human tumours evolve when engrafted in mice and (ii) the treatment’s impact on the immune environment.

Since its start in 2021, the study primarily focused, as planned, on the analysis of the preclinical efficiency of several inhibitors and the identification of their optimal dosage.

Financed: 500 000€
Duration: 2 years
Countries: France & Germany
Disease: Rhabdoid tumour
Status: Ongoing since 2021



Wings to empower immunotherapy

Osteosarcoma is a very challenging paediatric tumour to treat in paediatric oncology. Over the last 30 years, there have been no improvements in treatment despite a dismal survival rate in those children who develop metastasis.

Immunotherapy has led to spectacular results in blood cancer, both for paediatric and adult patients who had no other treatment options.

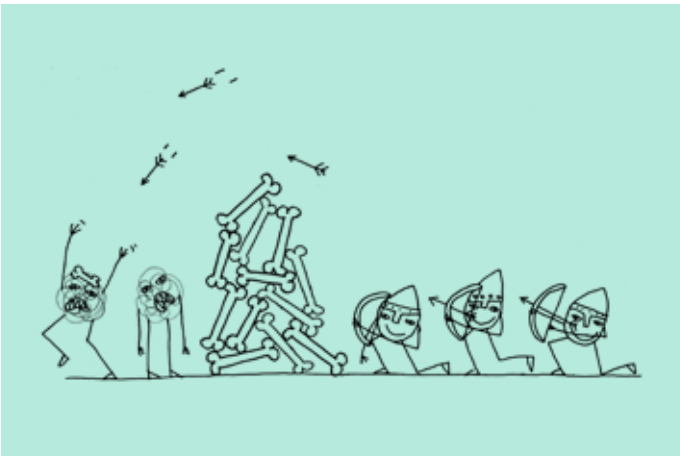
However, to this day, it has not been possible to replicate this success in patients with solid tumours like osteosarcomas. This is mainly due to the barrier posed by the hostile microenvironment surrounding the tumour. This barrier prevents the migration of white blood cells and diminishes their capacity to fight a tumour.

The “IMAGINE” project aims at overcoming this barrier in paediatric osteosarcoma using an innovative, inexpensive, non-invasive and easy to implement approach. Patient’s own re-engineered white blood cells will be loaded with magnetic nanoparticles that can be guided to the tumour through a magnetic field.

This approach not only will increase the concentration of white blood cells at the tumour site but will minimise toxicities on healthy tissues. If the IMAGINE project’s results are conclusive, the next step will consist in the opening of an early phase clinical trial to test this technology in order to increase the survival rates and quality of life of young patients with osteosarcoma.

Since its start in 2021, the project demonstrated good progress in the evaluation of the most optimal method to generate magnetic nanoparticles and proved their absorption in some immune cells as well as the lack of effects on the viability of these cells.

Financed: 500 000€
Duration: 2 years
Countries: Spain, France & Norway
Disease: Osteosarcoma
Status: Ongoing since 2021



1.1. Research Projects

A molecule to sabotage neuroblastoma!

Survival chances of children with an aggressive form of **neuroblastoma** are direly low and survivors often suffer from long-term side effects.

The projects' researchers recently identified a key protein "RRM2" that neuroblastoma cells rely on for sustained growth.

In this project "RESTRAIN", researchers will create mouse and zebrafish models to cause a degradation of the RRM2 protein with the objective to improve our understanding of the role of RRM2 during neuroblastoma tumour formation. These novel preclinical models will also be explored to identify synergistic novel drugging strategies by using available small molecules.

In addition, the objective is to discover as many other proteins as possible that together with RRM2 play a crucial role in neuroblastoma cells growth and thus serve as novel targets for future therapy.

Since its start in September 2021, researchers focused on the creation of the necessary materials to generate animal models (mice and zebra fish).

Financed: 500 000€
Duration: 2 years
Countries: Belgium and United Kingdom
Disease: Neuroblastoma
Status: Ongoing since 2021



Long-term follow up of patients

Today, in Belgium, 87% of children with cancer are alive five years after their initial diagnosis. However, up to 90% of them are exposed to increased comorbidities risk and premature mortality (up to 90% patients).

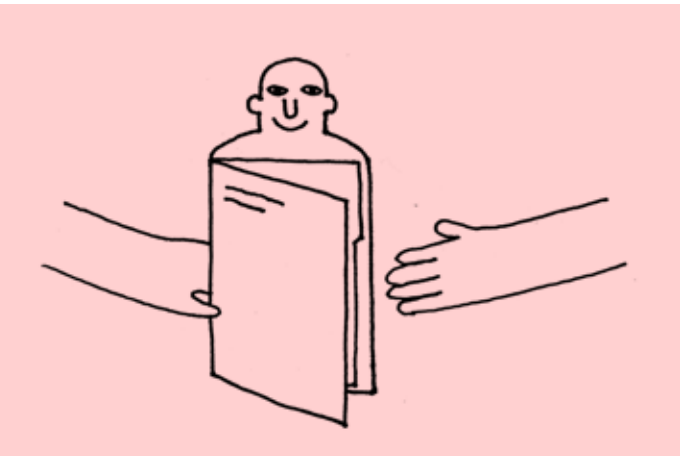
Besides, in Belgium, there is neither an organised specific long-term follow-up plan adapted to their medical history nor a specific reimbursement for such follow-up consultations.

The Long-Term Follow-Up project aims at setting up a single national standardised database with all clinical information available for Belgian patients: type of treatment received, relapse, secondary cancers, acute toxicity, 5-years survival.

As a result, the aim of the project is to:

- Improve our understanding of long-term side effects caused by the treatments received by young patients
- Provide each patient with a summary of the treatment received and a tailor-made follow-up plan to empower them to prevent and reduce those long-term side effects
- Enable the Belgian paediatric oncology units to contribute to the European research effort by enriching European databases
- Compare the survival and long-term toxicity figures affecting the Belgian patients with that of patients from other European countries
- Advocate with the Minister of Health the set-up of a specific financing for the "long-term follow-up" consultations.

Financed: 203.000€
Duration: 2 years
Country: Belgium
Diseases: All types of cancer
Status: Ongoing since 2021



E-SMART: an innovative pan-European clinical trial

E-SMART is a **platform clinical** study that allows to test several novel drugs in development for adults simultaneously and promising for paediatric cancer.

This clinical trial is open to all patients in therapeutic failure, whatever their cancer type and gives them access to innovative and targeted therapies.

This study initially opened in France in 2016 and has now been extended to the Netherlands, UK, Spain, Italy and very recently Denmark. Since its opening, 14 treatment arms have been opened, which allowed to test 19 drugs in total (single agent or combination), including 7 for the first time in children. Three new treatment arms are currently in preparation. As of 10 December 2021, 187 patients had been enrolled in this study through 19 investigation centres. This project is coordinated through the ITCC network (Innovative Therapies for Children with Cancer) and is simultaneously funded by Imagine for Margo (France) and Fondatioun Kriibskrank Kanner (Luxembourg).

Our financial support allows the opening of the 3 new treatment arms.

Financed: 413 571 €
Duration: 4 years
Countries: France, Netherlands, UK, Spain, Italy & Denmark
Disease: All paediatric cancers
Status: Ongoing since 2020



A clinical trial for refractory or relapsing solid tumours

This innovative clinical trial will test the combination of three classical **metronomic chemotherapies** with a "PD-1 **checkpoint inhibitor**" or Nivolumab®. This trial allows children to benefit from **immunotherapy**.

The clinical trial is taking place in six French hospitals and in three in Belgium (Ghent, Leuven and Brussels / Saint-Luc). It is open to patients with a solid tumour who do not respond to standard treatments or who are in relapse. The trial is split in two phases: a first one where the toxicity of the proposed combined drugs is analysed and a second one where the efficacy of each combination is compared. In 2020, a total of 16 patients in 3 treatment arms were recruited for the first phase.

Now, a total of 102 patients will have to be recruited for the second phase to complete the trial. As the pandemic caused some delay in the completion of the programme steps, the inclusion of all patients in the second phase is planned from March 2021 to January 2024.

In 2020, 16 patients, split between 3 treatment arms, were recruited for the first phase. It lead to the conclusion that the association of Nivolumab with the **three metronomic chemotherapies** (arm C) is safe (toxicity).

The second phase (opening of arm C and analysis of efficacy of the addition of Nivolumab) started in March 2021. 102 patients will have to be recruited by January 2024 in order to complete the trial. Currently, 13 patients have been randomized into the study, including two patients in Belgium (one in the University Hospital of Gent and the other one at the University Clinic Saint-Luc).

Financed: 150 000 euros
Duration: 3 years
Countries: Europe
Disease: Solid tumours
Status: Ongoing since 2018



1.1. Research Projects

Improving our understanding of the resistance mechanisms of high risks cancers

In the event of inefficacy of so-called “first-line” standard treatment, the orientation towards new therapeutic approaches and the understanding of the resistance mechanisms must be based on an in-depth analysis of the biological characteristics of the tumour and the analysis of the interactions between the tumour and the patient.

This project aims at allowing a full molecular analysis of the tumour upon diagnosis for the children and adolescents with a high-risk cancer, thanks to advanced technologies, including **high-debit sequencing**. By analysing blood samples (including the circulating DNA of the tumour cells) during the treatment and follow-up, researchers can then keep track of the modifications of those molecular profiles. The collected molecular information is compared with the clinical results of patients (response or lack of response to treatment) to refine our understanding of the response to treatment.

This project will allow for a better understanding of the avoidance and resistance mechanisms to the standard treatments. In conjunction with other ongoing projects, the results of this analysis will enable doctors to swiftly redirect patients towards the best therapeutic strategies. As of December 31st, the study was open in 30 centres with 412 patients included in the protocol. The molecular and immunologic analysis and the structuring of the latter analysis are underway. The major hurdles caused by the world pandemic (lockdowns, homeworking and material shortages...) caused delays in the implementation of the programme milestones, notably with respect to the recruitment of patients and the technical analysis. However, the preliminary results obtained through the immunologic analysis are extremely encouraging.

Financed: 200 000 euros
Duration: 6 years
Countries: France
Disease: High risk cancers
Status: Ongoing since 2017



1.2. Advocacy

KickCancer's second line of action to improve treatments available for children with cancer is to connect with all the players in the field (doctors, researchers, regulatory authorities, pharmaceutical industry, and other philanthropic organisations active in the field of cancer). Understanding and listening to the players' constraints is crucial to create a more favourable regulatory and cultural environment for a swifter access to innovation for children with cancer. KickCancer's goal is to make the system more efficient.

FIGHT KIDS CANCER

Advocacy is not limited to political actions. We can also improve research and treatments for children with cancer by influencing how research is conducted and financed. Paediatric cancers are a group of cancers, which are all rare cancers –even those with the highest prevalence in children.

In order to be effective, research needs to happen at an international level. This is why KickCancer was so keen to initiate a European programme: FIGHT KIDS CANCER. FIGHT KIDS CANCER is a joint initiative of KickCancer, Imagine for Margo (France) and the Kribskrank Kanner Foundation (Luxembourg) aiming at promoting the most innovative treatments through collaboration and funding research against childhood cancer at the European level. The FIGHT KIDS CANCER programme includes annual calls for projects and the supervision of the funded projects.

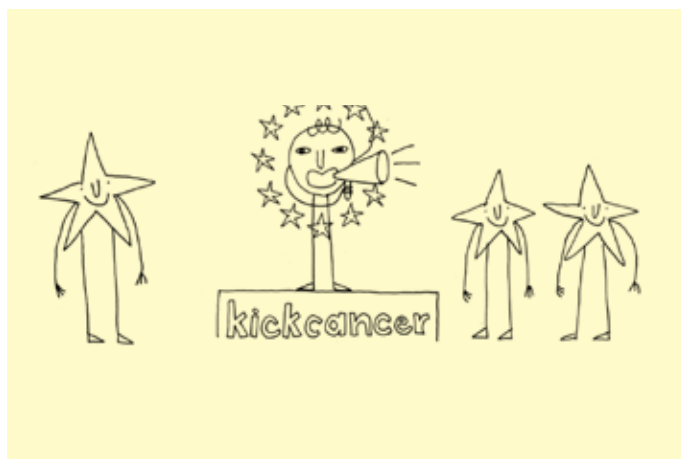
The ambition is definitely to include more organisations in order to increase the amount of the calls over time.

The FIGHT KIDS CANCER programme offers the following advantages for patients and researchers:

- It finances projects **across countries**: this enables researchers to collaborate at a European level while looking for one single source of funds. Now, consortia can apply for one grant (vs. one in each participating country) and report to one single group of funders. It is more efficient.
- It finances **patients-centric projects**: impact for patients, next to scientific excellence and adequate use of funds, is a major selection criterion.
- It allows the funders to push a **political agenda in research**: data-sharing, open-source publications, quality of life for patients....
- The recurring (yearly) nature of the programme gives **long-term perspective to researchers** when they nurture a project: they can keep on fine-tuning their ideas before applying because they know there will be another call in the coming year.

In 2020 et 2021, our calls for FIGHT KIDS CANCER projects have resulted in a selection, by independent international experts of respectively six and five European-wide research projects for a total amount of 6.530.000 €, 1.525.000 € of which are financed by KickCancer (please find the projects described above).

In October 2021 we have launched a third call for projects for the year 2022 — for a total amount of 4 million euros. KickCancer intends to contribute an amount of 1 million € thanks to RUN TO KICK. This call for projects has already met with enormous success in terms of the number and quality of applications received.



Collaboration with the Belgian Society for Paediatric Haemato-Oncology

In Belgium, most young patients are treated in the framework of a clinical trial. These are in most instances **late-phase clinical trials**.

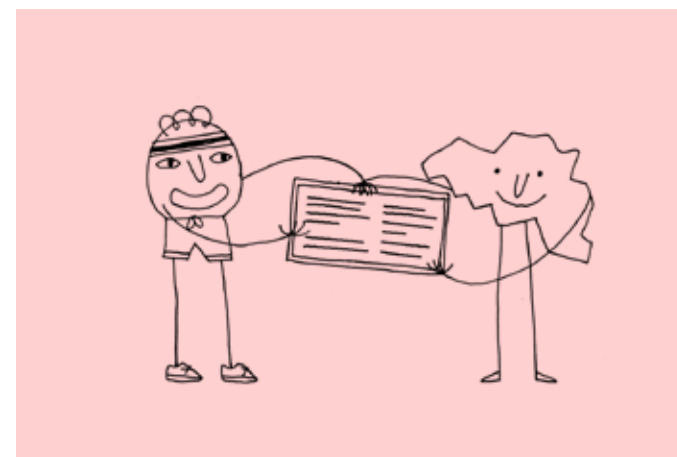
The protocols for these late-stage clinical trials are designed in the framework of SIOPE's (Société Internationale d'Oncologie Pédiatrique Europe or the European Society for Paediatric Haemato-Oncology) disease-specific collaborative groups where specialists of one disease meet and jointly define the best treatment strategies for this disease. The clinical trials' protocols are defined at the European level but the financing of the projects often has to be sought by each participating country or site.

In Belgium, the Belgian Society for Paediatric Haemato-Oncology (BSPHO) also coordinates and initiates the participation of the Belgian centres in international academic clinical trials.

Since 2020, KickCancer has been proudly supporting the BSPHO's effort to bring those crucial clinical trials in Belgium by structurally financing the work of its coordination cell (118.000 € per year). This ensures access the best care for young patients treated in Belgium and a sustained participation of our oncology centres to the European research effort.

In 2021, KickCancer strengthened its collaboration with the BSPHO by signing a collaboration agreement under which we commit to support each other and define clear procedures for the selection and funding of research projects.

During our first review meeting in December 2021, KickCancer committed to finance three clinical trials in Belgium in the following disease areas: high risk neuroblastomas, Langerhans cell histiocytosis and **rhabdomyosarcomas**. KickCancer will also finance for an additional year the long-term follow-up registry of Belgian survivors. This total commitment amounts to 740.000€ over three years.



European Institutions

European regulatory activity in 2021 was the logical continuation of that of 2020... a whirlwind of initiatives, which reinforced the milestones set in 2020.

If you have read our 2020 report (of course you did!), you might remember that Delphine Heenen became a member of the Regional Committee of the overarching association Childhood Cancer International Europe (CCI-E) and that she took over the responsibility of their transversal pillar "European Affairs".

In this capacity, she contributed to shape their European strategy on behalf of patients, survivors or parents.

In 2021, we therefore responded to **4 public consultations and one roadmap**, each time both on behalf of CCI-E and KickCancer (10 contributions in total!):

- The consultation on the application of **Patients' Rights in Cross-Border Healthcare** which allows patients to seek treatment in another country of the European Union while benefiting from reimbursement of their treatment. Today, there are still too many administrative barriers to the travel authorisation and the reimbursement of travel expenses is often largely insufficient. In paediatric oncology, moreover, we ask that participation in a clinical trial also be considered as providing care, since most young people with cancer are treated within the framework of a clinical trial.
- The consultation on the **European Health Data Space** allowed us to express our asks for the protection of the privacy of patients but also our wishes in terms of data sharing – sharing is essential to generate progress in the field of research or to develop relevant policies in the field of healthcare.
- The roadmap and the consultation on Revision of the **EU General Pharmaceuticals Legislation** allowed us to highlight our vision on access to innovation (availability in all countries and affordability) and the issue of responding to unmet medical needs.
- The consultation on the revision of the Regulations on **Medicines for children and rare diseases** through which we want to facilitate access to innovation for young cancer patients, whether through drugs developed for adults that would be translated for paediatric use because their mechanism of action is relevant or drugs developed 'de novo' for the benefit of young patients.

These last two texts will be discussed in the European Parliament end of 2022. These are particularly significant and raise a lot of hopes for our community.



1.2. Advocacy



The Patients' Voice

In 2021 KickCancer truly became a patient's organisation by adding a new stream to its strategy to defeat childhood cancer: the creation of a Patients' Committee!

This Committee will structurally empower the voice of young patients and their parents and thereby contribute to improving the quality of care and advocacy for paediatric cancer patients in Belgium and in Europe.

The Committee is conceived in three layers:

- **Informed patients** who wish to be specifically informed about our advocacy activities and subscribed to our "patients-specific" newsletters.
- **Engaged patients** who accept to participate in our activities by taking surveys or by contributing to focus groups discussions. The purpose is to create a group of patients that will faithfully represent the patients' population in order to reflect their needs and, ultimately, to improve research or the regulatory environment.
- **Expert patients** who ambition to participate more actively. Our expert patients were selected after a recruitment phase and they completed a specific training conceived in collaboration with the PEC (Patient Expert Centre). The training allows them to elevate their patient's experience to an expert level. They can also contribute to more patient-centric research and to an improved regulatory environment. Finally, they can offer professional peer-to-peer support to newly diagnosed patients and their families.

The first certified "Expert Patients" of KickCancer's Patients Advocacy Committee graduated on December 2nd, 2021 and have already been involved in several internal and external projects.

1.3. Events



ECLAIR DAY

Once a year, gluttony is a good deed: eat a good dessert and give childhood cancer a taste of its own medicine.

The second edition of Eclair Day took place on November 20th, 2021. Each participating (pastry) baker offered its signature éclair at a different price than its regular eclairs. This amount was entirely donated to the KickCancer Foundation to finance research on children's cancer. This new action could claim a quite prestigious godfather: Pierre Marcolini himself. This second edition was a sweeping success, and it was impossible to resist the temptation to organise a third edition. Take your diary and pencil this date: Saturday November 19th, 2022 will mark the third edition of Eclair Day!



The charity Tombola of Angèle

Our ambassador Angèle organised a charity tombola for KickCancer, which, quite opportunistically, kicked off on February 15th, 2021, International Childhood Cancer Day.

Thanks to Angèle's dedicated involvement of and a spectacular cast of prizes, KickCancer could count on buyers from Belgium, France, Switzerland, Canada, the United Kingdom, United States and even Australia. As a result, more than 200,000 euros were raised for KickCancer and will be invested in research on childhood cancers.

This event also allowed us to benefit from exceptional media exposure, which culminated in an Instagram live on March 25th, 2021, during which the name of the winners was revealed.



RUN TO KICK

KickCancer's fourth edition of RUN TO KICK, our solidarity and family race, took place on September 26th, 2021. In 2020, we had proudly connected together 750 runners that had jointly fundraised the fantastic amount of 610 000 euros. In 2021, we were blessed to find our way back to togetherness and we spent a glorious morning with you in the Laeken Park.

Seeing each other again was plain magic and the (quite necessary) sanitary measures did not affect our joy to the slightest extent. No, in 2021, the real challenge laid rather in the fact that Belgian people already were overly solicited for various social events, from weddings to family celebrations... But we managed to convince you to spend your Sunday morning with us. Because who is not afraid of anything? That's us!

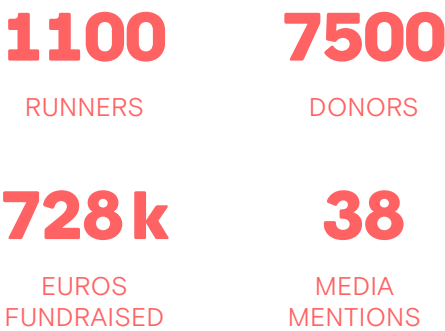
1100 people came and ran or walked by the Atomium and our ambassador Niels Destadsbader honoured us with an energetic contribution and enthusiastic presence!

The joy of being together was palpable and so was the emotion... We were really happy to see that the clear winner of the race was solidarity with families with a child with cancer.

This year, we have reached the record amount of 728 000 euros. Thanks to our sponsors who finance RUN TO KICK organisation cost, among which Delhaize is the largest, we were able to invest 100% of this amount in innovative FIGHT KIDS CANCER research projects.

For 2022, we are aiming at the million (yes, we are!). We will welcome you for a cool and happy event in the Laeken Park again on September 25th, 2022.

Register now for September 25th, it will be fun, moving and above all full of joy. And you will contribute to financing the best innovative research projects in Europe.





HET familie-event dat je niet mag missen – omdat elk kind met kanker de beste behandeling verdient!



Une course familiale avec un juste équilibre entre le fun d'une course et le sérieux des traitements pour soigner les cancers.



Une organisation parfaite et une ambiance excellente pour une formidable cause. Participer sans modération !



A nice event to raise money for the best cause. And lots of fun for the kids!



1.4. Raising awareness

Medias

KickCancer benefited from an increased media attention thanks — in part — to Angèle’s and Niels support to our cause. As a result, we benefited from a peak of articles in the written press and on the radio in February, March and September 2021 during Angèle’s tombola and when Niels announced his participation in RUN TO KICK.

Pierre Marcolini’s involvement for Eclair Day also fostered great media attention.

In 2021, we continued our relationship with a Public Relation agency, Talking Birds, who ensures our media presence while conveying the right messages about paediatric cancers.

Awareness campaign

It is important for KickCancer to raise awareness on paediatric cancer and the importance of research. Most people think that when they support research on cancer, children will benefit from their gift. It is hardly the case.

With the help of our communication agency, Base Design, we developed a new campaign on the theme of child plays whereby kids challenge each other.

Are you game? Well, when it comes to cancer, our desire to play tends to fade... We used that contradiction to strike people’s minds.

Our awareness campaign ran in September on digital media combined with radio. We also managed to secure good press and television coverage (see above, during Angèle’s tombola and the month preceding RUN TO KICK).

The National Lottery

KickCancer has been blessed with the support of the National Lottery and of its players since 2019 in order to carry out our awareness projects. In 2021, this partnership was marked by a support to the organisation of the Éclair Day, which paved the way for a strengthening of this partnership to continue this collaboration in 2022. One thing is for sure: the National Lottery is much more than just games.

Thank you for joining our family, kickers!

4

TELEVISION
APPEARANCES

212

ARTICLES IN
THE WRITTEN OR DIGITAL PRESS

9

RADIO
SHOWS

2. Financial Report

2.1. Overall results

As you know, KickCancer works closely with the KickCancer Fund, a Fund dedicated to research in paediatric oncology managed by the King Baudouin Foundation. In this section, you will find our overall results, adding those from the KickCancer Foundation to the KickCancer Fund.

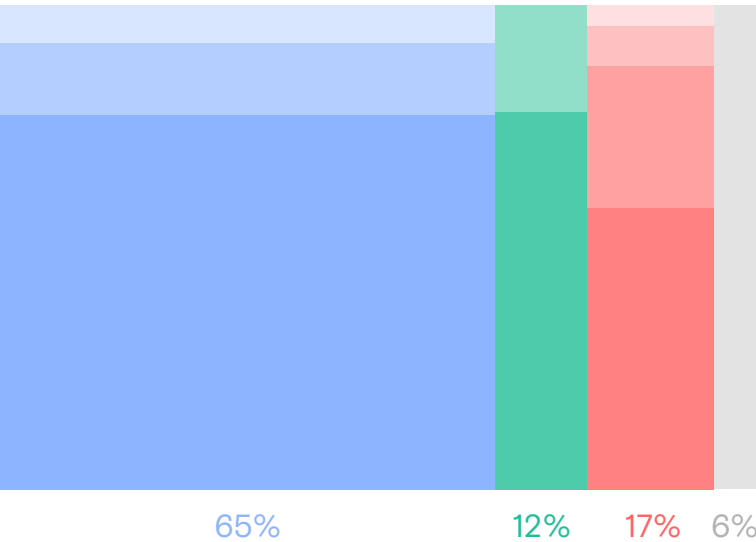
Sources of funds



TOTAL **1 805 864**

Registrations	19 728
Donations	1 786 136

Usage of funds



TOTAL **1 805 864**

PROJECTS	1 183 350
Advocacy	93 051
Reserve for future projects	174 517
Invested projects	915 782
AWARENESS	220 018
Organisation of events	171 418
Awareness campaign & material	48 600
ADMINISTRATION	301 355
Investments	12 991
Operational reserve	25 000
Administrative costs	88 283
Salaries	175 080
AVAILABLE RESERVE	101 141

2.2. Fondation KickCancer

In this section, you will find the results generated by the KickCancer foundation alone.

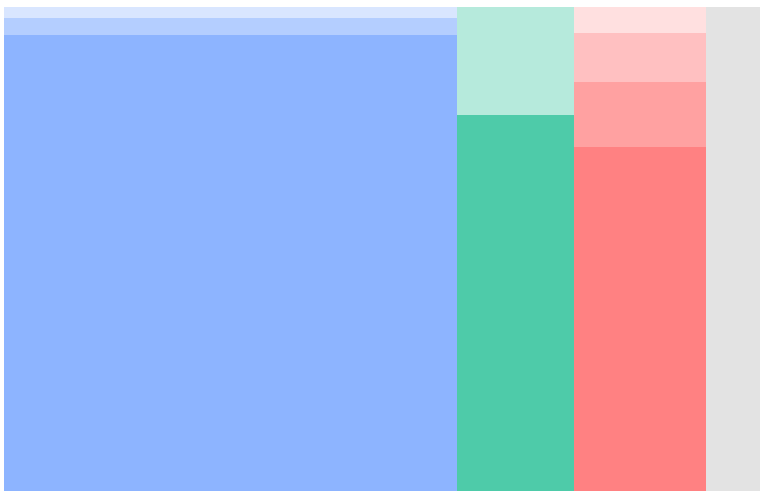
Sources of funds



Registrations	19 728
Donations	381 418
King Baudouin Foundation transfer	1 015 088

TOTAL **1 416 234**

Usage of funds



60% 16% 17% 7%

PROJECTS	848.722
Reserve for future projects	18.000
Advocacy	30.591
Invested projects	800.132
AWARENESS	220.018
Awareness campaign & material	48.600
Organisation of events	171.418
ADMINISTRATION	246.352
Investments	12.991
Operational reserve	25.000
Administrative costs	33.281
Salaries	175.080
AVAILABLE RESERVE	101 141

TOTAL **1 416 234**



3. KickCancer Team

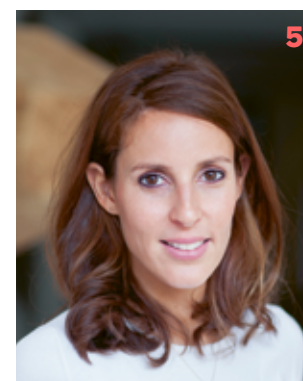
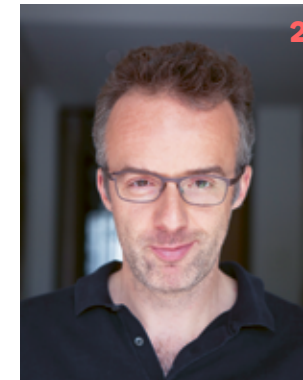
3.1. The board

Founders & Family representatives

- 1** Delphine Heenen
Managing Director and Founder
- 2** Gilles Dal
Director and Founder
- 3** Jean-Charles van den Branden
Director and Founder
- 4** Marc Dal
Director and Founder
- 5** Céline Ghins
Director
- 6** Hélène d'Udekem d'Acoz
Director

Professional directors

- 7** Deborah Janssens
Lawyer partner at Freshfields Bruckhaus Deringer
- 8** Christophe De Vusser
Director at Bain & Company
- 9** Frédéric Rouvez
Founder and Managing Director of Exki
- 10** Jo Van Biesbroeck
Director at Telenet SFI (Lux) and Matexi
- 11** An Winters
Consultant at Russell Reynolds Associates



3.2. Permanent team

The permanent team consists of seven people, Delphine and six other kickers with superpowers:

- 1 Nina Estelles**
Kicker-in-Operations
- 2 Nathalie De Clercq**
Kicker-in-Marketing
- 3 Caroline Stals**
Kicker-in-Advocacy
- 4 Alice Gerbaux**
Kicker-in-Empowerment
- 5 Eric Peeters**
Kicker-in-Administration
- 6 Delphine Messiaen**
Kicker-in-Communication



Help us to kick and make
a difference for kids with
cancer by making a donation
and amplifying our voice
on social media.



To make a donation

Fondation King Baudouin — KickCancer Fund
BE10 0000 0000 0404
Communication: 016/1960/00070

All donations from 40 € or more are tax derivable in Belgium.
The Foundation accepts dual legacies and can help you put them in place.
More than 80% of your donations will directly fund research or will go
to our activities to defend children with cancer, less than 20% will be used
for our communication, fundraising and administration.

Contact us: info@kickcancer.org
www.kickcancer.org

**CURE.
DON'T
CRY.**

kickcancer

Contact

info@kickcancer.org
www.kickcancer.org

KickCancer Public Interest Foundation
24 rue de l'Aurore – 1000 Brussels