kick cancer

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

Annual Report 2023

A few key metrics

3 million euros raised over one year – and more than 11 million over the first six years

10 new research projects financed for more than 1,5 million euros

A first project "by patients, for patients": MY COMPANION – Support kit, for 0,3 million euros, now distributed in all Belgian hospitals

A total investment of 300 000 euros in patients' empowerment

A total investment of more than 100 000 euro in advocacy

2 400 runners participating in RUN TO KICK and more than 16 000 donors who supported KickCancer

More than 210 mentions in the press

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

2 kicking ambassadors: Angèle and Niels Destadsbader

My dearest kicking friends,

You are reading our 6th annual report, and we are excited to bring you the excellent news that we kept calm and yet carried on growing by leaps and bounds!

We fundraised 3 million euros in 2023, gathered 2 400 runners for RUN TO KICK and organised the first edition of an event that is yet to become an art-lovers' classic: The KickCancer Collection at Art Brussels, the leading Belgian contemporary art fair.

These are naturally the signs of your support that we welcome with gratitude while aiming to stay close to our core nature: being young at heart.

After the 2022 RUN TO KICK groundbreaking record of 1 million euros in fundraising, we were anxious to reach even higher summits in 2023 but you did it for us! **Thanks to the enthusiasm of 2 400 runners, we raised 1,2 million on D-Day and another 70 000 in the month that followed**.

We invested the entirety of that amount in 9 FIGHT KIDS CANCER research projects. Thanks to the inclusion of two new long-term members to FIGHT KIDS CANCER, CRIS Cancer (Spain & UK) and KiKa (Netherlands), we ended up in an unusual situation: we had more funds than excellent research projects to fund.

Did we, as a result, feel like “our mission is accomplished”? Not quite yet! On the contrary, we interpreted this situation as a new proof that the field of paediatric cancers must become more appealing to attract more (young) researchers: more researchers, more ideas and more projects. More projects, more chances for children and young patients to cure without long-term toxicity!

We scanned funding opportunities offered in other research domains for inspiration and discovered the concept of “innovation award”. An innovation award is a research grant where one supports a researcher in their endeavour to grow without tying the funds to a specific project. We partnered with a well-renown organisation from the United States, the St. Baldrick’s Foundation, to organise **a joint innovation award that would promote thinking outside the box, true innovation, excellent quality of the science and potential for clinical impact**.

The request for proposals opened in November 2023 and we selected our candidate in April 2024 while the prize was officially handed over in May during the SIOPe annual conference (Société Internationale d’Oncologie – Europe).

Now, for the 2024 FIGHT KIDS CANCER call, we will be focusing on brain tumours: for one, because brain tumours are the #1 killer of children with cancer. For two, because until 2022, we had funded too few projects in this disease area and we felt like we had to put those patients on the forefront of our priorities. Interestingly, we received a lot of applications for brain tumour projects

in our 2023 call already. However, focusing our call on one disease area forced us to initiate discussions with the researchers on their actual needs and reconsider our standard specifications for research projects. As a result, we adapted the duration and amounts granted per project for the 2024 call.

In December, our support kit for patients, MY COMPANION, could finally be distributed in the 7 Belgian hospitals with a paediatric oncology unit. Not only is it a very useful tool, it is also incredibly beautiful and handy to use (can you recognise the sounds and rhymes of a proud mamma…?). It took 6 patient advocates, many healthcare professionals, 2 kickers, one graphic designer, one object designer, one cartoonist and 2 copywriters to get this project out of the ground. You can discover more on what it really looks like on page 37.

Although we cannot claim to have become 100% reasonable in our 6th year, we did start reaping very tangible fruits from our work. As a result, somehow, we have become a more “mature” organisation. In practice, just before Christmas, we received two incredible “gifts” — seeds that

we sowed and flourished. First, following our 2022 conference on the reimbursement of several off-label, but “standard of care drugs”, we could reach an **agreement with the National Institute for Health and Disability Insurance (NIHDI or INAMI/RIZIV) to obtain a structural reimbursement for 50 drugs and a framework to adapt the list of drugs annually** (see page 38 for more info).

Our second achievement followed because of our 2023 conference on the special needs of adolescents and young adults with cancer (AYA). Not only did we build a strong relationship with 2 adult sister organisations (Kom op Tegen Kanker and the Foundation against Cancer), but **we also contribute to the creation of a working group with the NIHDI to set up specific AYA care teams within 6 reference hospitals** (the university hospitals) and awareness on their needs in all hospitals with a cancer unit (see page 38 for more info).

Finally, we could also witness with joy that awareness on paediatric cancer received a definite boost in 2023, with a splashing action in Antwerp where local bakers reproduced the famous Ensor painting “The Intrigue” in eclairs, an on-stage interview of “yours truly” during the

women entrepreneurs' conference "Generation WOW" and a very humbling prize of "Woman of the Year" granted by Elle Belgium in the category "Prize of the Jury".

These titles and events that put KickCancer on the front stage are only possible thanks to you, our wonderful supporters. In 2023, we did feel the warmth of your support every single day. We hope to renew this thrill in 2024, so please: stick with us and children with cancer!

Delphine Heenen
Kicker-in-Chief and Managing Director

Our mission

We want to cure every child with 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 on 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 side effects. Survivors represent about half a million people in Europe today. We must make sure that those long-term effects 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 child's 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 these is divided into several subgroups. 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?

200 new drugs for adults vs. 17 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 who is 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 their 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

AYA

AYA is an acronym that stands for adolescent and young adult. AYA oncology is cancer care, or research focused on young people diagnosed with cancer. The age range is not unanimously agreed upon, but it includes people between 15-17 up to 35-39 years of age.

Blood-brain barrier

The blood-brain barrier is a physiological barrier between the blood and the central nervous system. Most pharmaceutical anticancer drugs do not cross the blood-brain barrier (too “big molecules”), so it prevents an adequate drug delivery to tumours located in the brain.

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 adaptive cell therapy, adoptive immunotherapy*, or immune cell therapy.

Classical Hodgkin lymphoma (cHL)

Hodgkin’s lymphoma is a type of cancer that affects the lymphatic system, which is part of the body’s germ-fighting immune system. In Hodgkin’s lymphoma, white blood cells called lymphocytes grow out of control, causing swollen lymph nodes and growths throughout the body. cHL accounts for 15% of all cases of cancer in children and adolescents and represents the first cause of cancer during adolescence.

Diffuse intrinsic pontic gliomas (or DIPG)

A type of brain tumour for which there is currently no cure. Research on 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 sarcoma

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

Genetic mutation

Alteration of the genetic material (the genome) of the cell, more or less permanent, which can be transmitted to future cells during cell reproduction.

Genomic technologies

The highly sensitive genomic technologies allow us to monitor the response of leukaemia* to therapy: the sensitivity of these technologies to detect MRD (“measurable” or “minimal” residual disease), opens the way to a personalised adjustment of the treatment.

In practice, a child with an excellent response to therapy (translated by very low to negative MRD), requires less toxic chemotherapy to achieve remission. Conversely, a child with a weak response to initial therapy (translated by a high MRD), will require an intensive chemotherapy and possibly the addition of a bone marrow transplant.

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 can detect 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*.

GLOSSARY

In vitro models

In vitro models are medical procedures, tests, and experiments that researchers perform outside of a living organism.

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 (ALL and AML)

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. The paediatric forms of leukaemia include the acute lymphoblastic leukaemia (ALL), the most common and curable one, and the acute myeloid leukaemia (AML), the least common and least curable one.

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 tumours).

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 chemo- therapy, 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.

Despite the current intensive treatments, the chances of survival for children with neuroblastoma that has come back (in relapse) remain unacceptably low, with less than 20% of children achieving a long-term cure while the treatment causes severe long-term side effects for survivors.

Organoids

Organoids are miniature replications of human organs. They have paved the way to a more reliable and faster technique to test new drugs preclinically as it allows the testing of up to thousands of drugs in one batch.

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 drop- ping 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.

Preclinical testing

Preclinical testing is a step in the development of a medical intervention (whether a drug or a medical device) where medical intervention is tested in animal models (mouse models or other small animals such as fishes). Nowadays, animal models are sometimes replaced by new techniques or medium such as egg yolks or organoids*.

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.

Targeted therapy

Targeted therapy is a type of cancer treatment that targets proteins that control how cancer cells grow, divide, and spread. Small-molecule drugs are small enough to enter cells easily, so they are used for targets that are inside cells. Monoclonal antibodies, also known as therapeutic antibodies, are proteins produced in the lab. These proteins are designed to attach to specific targets found on cancer cells. Some monoclonal antibodies mark cancer cells so that they will be better seen and destroyed by the immune system. Other monoclonal antibodies directly stop cancer cells from growing or cause them to self-destruct. Still others carry toxins to cancer cells.

1.1. Research Projects

KickCancer finances 27 research projects in the hope of improving treatments for children with cancer (in addition to the 5 research projects financed through the BSPHO, see hereunder).

1.1.1. NEW RESEARCH 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), CRIS Cancer Foundation (Spain), KiKa (the Netherlands) and KickCancer.

A clinical trial with a super strong combo to KILL brain tumours!

Brain tumours are among the most common and deadly solid tumours in children, adolescents, and young adults. In recent years, there has been little progress in the development of new drugs for these tumours.

Poly (ADP-ribose) polymerase inhibitors (PARPi) are drugs developed to treat cancers caused by specific genetic mutations. PARPi work by preventing cells from repairing themselves, leading to those cancer cells death.

Combining PARPi with chemotherapy has been shown to improve outcomes in other (adult) cancers. The aim of this project is to study NIRAPARIB, a type of PARPi that can cross the "**blood brain barrier**", in combination with IRINOTECAN, a chemotherapy used in several brain tumours.

This study will be part of a larger platform study: AcSé-ESMART, for which KickCancer already finances several arms. If this study shows encouraging results, NIRAPARIB with IRINOTECAN will be used in larger disease-specific studies to improve survival in patients with those specific brain tumours.

Financed: €513 500
Duration: 2 years
Countries: France, Austria, Germany, Denmark, Spain, Italy, the Netherlands, United Kingdom
Disease: All brain tumours
Status: Ongoing

Looking for the perfect clue to reduce toxicity in Hodgkin Lymphoma

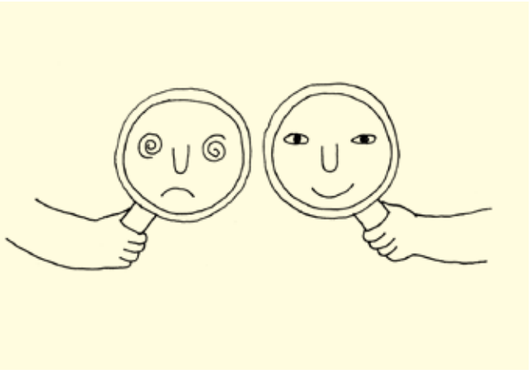
Today, almost 90% of patients with **Classical Hodgkin lymphoma** (cHL) achieve long-term survival with "classical" treatment options such as chemotherapy combined with radiotherapy. These treatments are very toxic during the treatment ("acute" toxicity) but can also cause long-term side effects ("long-term" toxicity). Accordingly, there is a need to focus on the reduction of both acute and long-term toxicity.

To reduce toxicity, we must reduce the intensity of treatments – but we can only do that by properly identifying first the patients with the "lower" risk types of cHL. This is what we call "risk stratification". Today, patients are categorised into risk groups based on imaging (such as scans).

This project ('Eurholy') will aim at defining a new methodology to categorise patients by developing a new biological marker that can be found in the patient's blood (**liquid biopsy**).

Thanks to a more accurate risk stratification, it will become possible to reduce the long-term toxicity of the treatments by identifying the patients for whom radiotherapy is not needed and by omitting some of the most toxic chemotherapy.

Financed: €500 000
Duration: 3 years
Countries: France, Germany
Diseases: Hodgkin Lymphoma
Status: Ongoing



Mini tools but maxi power to help kids with medulloblastoma!

In recent years, there has been little progress in the development of new drugs for brain tumours, including **medulloblastoma**.

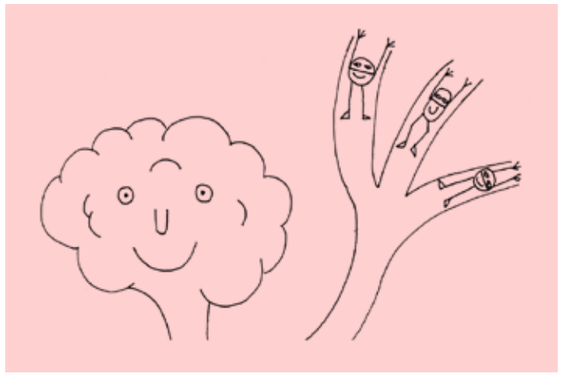
This lack of new drugs is caused by the difficulty to screen new drugs preclinically as potential candidates for the clinic. The most commonly used technique for **preclinical testing**, two-dimensional culture models in petri dishes, poorly represents the complex behaviour of the drugs in patients; as a result, there is a big discrepancy between the preclinical results and what is observed in the clinic.

Preclinical testing on mouse models is much more reliable (what is observed in a mouse is more likely to work in the clinic) but not very efficient in terms of number of drugs that can be tested. Better still, this project will use "**organoids**", which are much more efficient than animal models.

The "Medullodrug" team developed the first human organoid-based model for paediatric medulloblastoma and paediatric **high-grade glioma** opening the door for gaining unprecedented new knowledge into the development of paediatric brain cancer directly in a human system.

The aim of this project is to identify promising drugs, among drugs that have already been authorised, to initiate new clinical trials in medulloblastoma.

Financed: €478 300
Duration: 2 years
Countries: France, Italy
Diseases: Medulloblastoma
Status: Ongoing



Looking for DIPG's weak spots

Brain tumours are among the most common and deadliest solid tumours in children, adolescents, and young adults. The outlook for patients with **Diffuse Intrinsic Pontine Gliomas** (or 'DIPGs') is poor and they are almost completely incurable.

One obstacle to the development of efficient therapies for DIPGs was the lack of appropriate **in-vitro models** recapitulating with accuracy the characteristics of DIPGs. Moreover, most treatments used for this disease were developed for adults and show limited effect on children.

This project will use "**organoids**", which are much more efficient than animal models.

It has already been demonstrated that DIPG has a specific **epigenetic** profile; this project will also attempt to identify epigenetic dependencies and vulnerabilities of DIPGs.

As a result, this project will set the basis for the development of novel and personalised therapeutic strategies for this paediatric disease.

Financed: €500 000
Duration: 2 years
Countries: France, Austria
Disease: Diffuse Intrisic Pontine Gliomas
Status: Ongoing

1.1. Research Projects

Recognising super mean T-ALL cells to cure more kids!

Acute lymphoblastic leukaemia (ALL) can affect either B- or T-cells (B or T-ALL). The current cure rate amounts to about 80% of all patients.

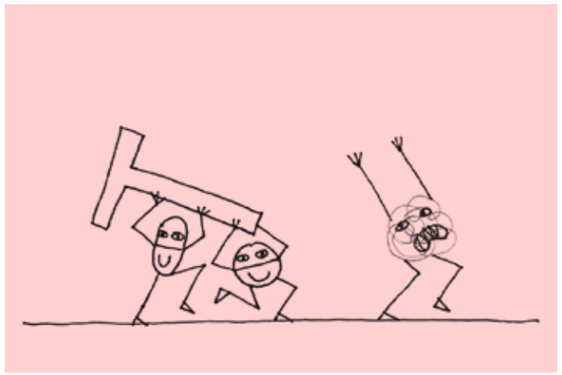
When a child with T-ALL does not respond to the initial treatment or when the disease comes back, his or her chance to cure falls below 25%. To improve those patients' chances of survival, we need to improve our understanding of the T-ALL biology and to identify "biomarkers".

14 European countries have joined forces in one single clinical trial for children and **AYA**s called "ALLTogether1". This wide clinical trial brings together patients' samples that can be studied.

This study will analyse changes in genes and proteins in resisting T-ALL cells. The researchers will use artificial intelligence to create computer simulations of the composition of the leukaemia cells to predict response to novel treatments. In addition, leukaemia cells will be tested in the lab to understand how possible combinations of existing drugs can kill leukaemia cells.

This project aims to develop a test platform to determine which combinations of existing drugs will be effective to treat patients with T-cell leukaemia. It will also speed up drug development and improve access to personalised treatments in the future.

Financed: €499 000
Duration: 2 years
Countries: The Netherlands, United Kingdom, Germany, Portugal, France, Ireland, Sweden, Belgium
Disease: T-cell Acute Lymphoblastic Leukaemia
Status: Ongoing



Understanding high-risk glioma cancer, cell by cell

In recent years, there has been little progress in the development of new drugs for brain tumours, including gliomas.

Targeted therapies are now increasingly used in clinic for children with high-risk cancers, who have exhausted all other standard therapeutic options. Meaningful responses to targeted therapies are seen in some but not all patients. Even when patients respond to treatment, long-term tumour control is rarely achieved, and it fails after a time as cancer cells start developing resistance to the novel targeted drugs.

This study aims to understand this development of drug resistance during treatment and optimise the detection of drug-resistant cells.

Researchers will sequence the tumour at a single-cell level. This will help to understand how, within a tumour, different cell populations reprogram themselves to escape targeted therapies. Both the disease and mimic treatment will be modelled in a lab: researchers will compare glioma tumour samples from patients that responded to targeted therapies to those that did not.

The knowledge generated by this study will be used to refine therapy, improve the selection and implementation of targeted therapies in clinical trials, with the ultimate objective to improve survival for children and adolescents with high-risk cancers.

Financed: €500 000
Duration: 2 years
Countries: Switzerland, France
Disease: Brain tumours/gliomas
Status: Ongoing

A beautiful skeleton for all (even after radiotherapy)!

One third of children with cancer will undergo radiotherapy as part of their standard treatment.

Children are still in development, which makes them very sensitive to radiations: radiotherapy can cause many long-term side effects (short stature, irregular body proportions, or spinal curvature). These disorders can be very severe, painful and debilitating.

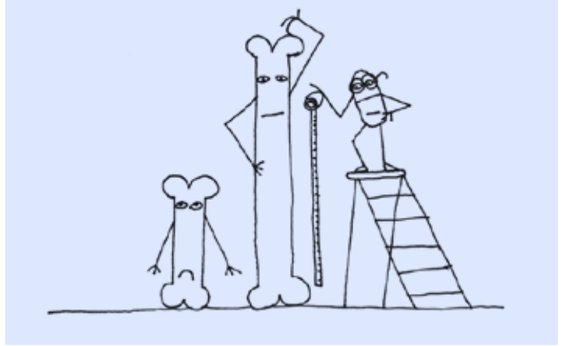
Growing bones are not normally the intended target of radiotherapy. Radiation oncologists will intentionally irradiate growing bones as evenly as possible to reduce the risk of curving.

More than 2,750 European children will receive spinal irradiation every year. The consequences are severe, with reduced final height and irregular body proportions. Approximately 900 of these children will develop spinal curvature.

When the skeleton stops growing these changes become permanent, and these childhood cancer survivors have limited treatment options.

For this project, researchers will develop state-of-the-art models to understand the underlying causes of radiation damage to the growing skeleton and test strategies to prevent the development of skeletal late effects.

Financed: €499 000
Duration: 2 years
Countries: Sweden, Switzerland
Disease: Radiotherapy side-effect
Status: Ongoing



Hypnotising brain tumour immune cells to help them fight with us and kill DIPG!

The outlook for patients with a **Diffuse Intrinsic Pontine Gliomas** (or 'DIPGs') is poor and they are almost completely incurable.

Considerable progress has been made in survival of young patients with many types of paediatric cancer, thanks to the positive impact of **immunotherapy**.

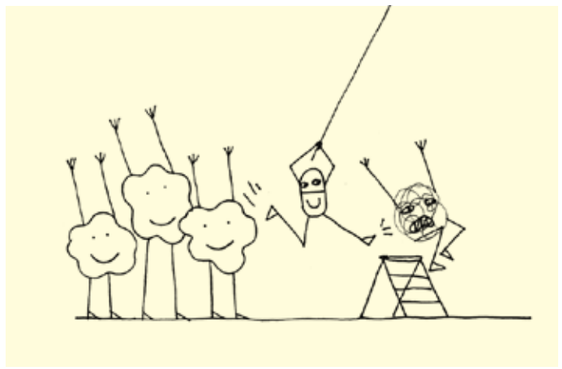
Unfortunately, so far, chemo- and immune-therapies against DIPGs have been investigated without success, mainly because of the **blood-brain barrier**. Besides, macrophages and microglia (immune cells located in the tumour) shut off the immune system and prevent it from recognising and killing tumour cells, which enables the tumour to further its growth.

As immune cells can reach every part of the body, the use of immunotherapy for brain tumours offers an efficient solution to hunt down the most distant tumour cells. Immunotherapy could even thwart the impact of macrophages and microglia and make them work against the tumour cells by helping them to recognise the "foreign nature" of brain tumour cells.

This project will try to bring into the brain tumour therapeutic agents that reactivate these macrophages and microglia, using non-invasive ultrasound waves to open the blood-barrier.

By bringing in therapeutic agents, the immune system can improve its ability to recognise and kill the cancer cells, not only locally, but also cells that have moved to different parts of the brain. If successful, this will lead to an increase of the survival rate and a better quality of life for children with brain tumour.

Financed: €424 500
Duration: 2 years
Country: The Netherlands
Disease: Diffuse Intrinsic Pontine Gliomas (DIPG)
Status: Ongoing



Looking for the perfect trick to differentiate kids with Ewing Sarcoma!

The standard treatment for **Ewing sarcoma** includes chemotherapy and local treatment with radiotherapy or surgery when possible. Over the last decades, no new effective drugs have been introduced in the frontline treatment, despite dissatisfactory survival chances.

In the years 2010, a new treatment against a specific target called IGF-1R, which is pre-dominantly present in Ewing sarcomas, showed promising results in some patients.

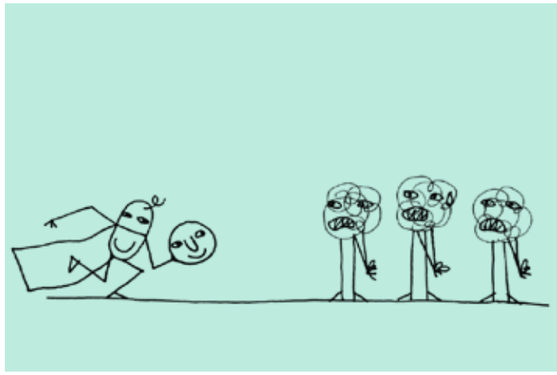
This project will study samples from patients included in a closed clinical trial where an IGF-1R inhibitor was tested to identify a biomarker that could tell apart patients that did respond from those who did not respond.

Besides, a new clinical trial will open shortly in the framework of eSmart where a new antibody called 'Istiratumab' will be tested that can target not only IGF-1R but also ERBB3 (a "bis-specific" antibody).

The researchers will perform biological studies with fresh tissue of patients' tumours, collected before inclusion in the eSmart clinical trial, and with plasma collected during the study. New technologies will be used to screen all biological elements which could be involved in the response or resistance to treatment.

The results could lead to an improved selection of patients for the next clinical trials with targeted therapy against IGF-1R and allow the development of new therapeutic strategies for patients with resisting or relapsing Ewing sarcomas.

Financed: €372 500
Duration: 2 years
Countries: France, Switzerland
Disease: Ewing sarcoma
Status: Ongoing



1.1.2. ONGOING PROJECTS

FIGHT KIDS CANCER projects

Unleashing the power of immunotherapy for kids with neuroblastoma in relapse

To this day, only one new type of drug has been developed specifically for patients with **neuroblastoma** and it is critical to identify new, more efficient and less toxic treatments.

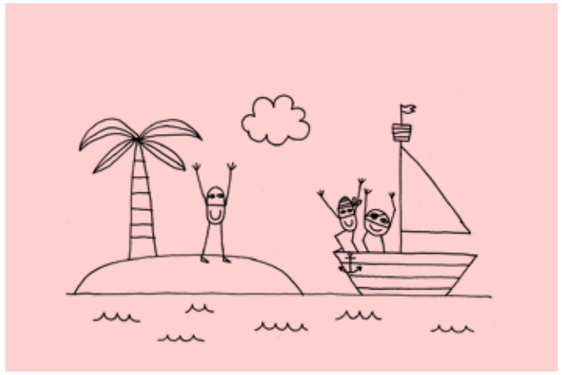
The BEACON 2 trial will test two new promising anti-cancer medicines that will be combined with chemotherapy.

The first drug will specifically target the blood vessels that help tumours grow. This could lead to the death of the tumour cells.

The second drug is an immunotherapy drug (**checkpoint inhibitor**) that should recognise the cancer cells as strangers in a patient's body to kill them.

As the BEACON 2 trial aims at recruiting 160 patients, it will confirm which of these two treatments is superior in a large group of patients. This is an essential step to change practice, so that the treatment can be given by doctors widely across Europe after the trial. It will also develop new combinations of drugs that improve the efficacy of **immunotherapy**, curing more children with fewer side effects.

Financed: €1 500 000
Duration: 3 years
Countries: United Kingdom, France, Switzerland, Belgium, Denmark, Ireland, The Netherlands, Spain, Czech Republic, Italy, Norway, Israel (Australia and New Zealand not funded by KickCancer)
Disease: Neuroblastoma
Status: Ongoing



Personalised yet NOT NICE treatment for leukaemia and lymphoma cancer cells

Leukaemia and **lymphoma** are the most common haematological malignancies in children and constitute almost half of all paediatric cancer cases. High-risk patients, who do not respond to standard therapy or suffer from relapse (when the disease comes back), only have a 27% survival rate.

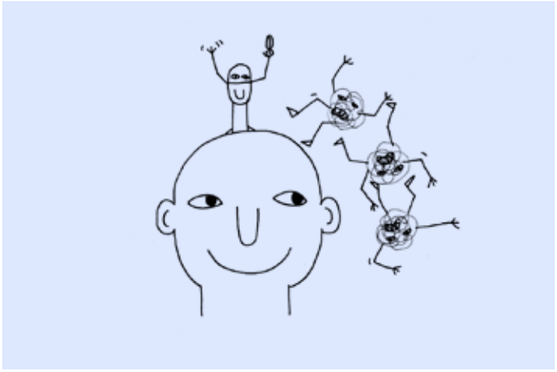
The HEM-iSMART has been developed for those children, who will receive a treatment corresponding to the specific genetic alteration(s) present in their tumour. It aims at recruiting sixty patients in total.

Research in cancer genetics have facilitated the development of drugs that specifically target mutations found in cancer cells and the mutated proteins produced by those cancer cells.

Targeted drugs could revert the activity of altered proteins, stop cancer growth or induce tumour cell death. As a result, such drugs could increase the chances of survival for children with relapsed leukaemia or lymphoma.

The HEM-iSMART trial aims at testing four new therapies, each one matching a specific genetic alteration present in the tumour of the patients.

Financed: €1 500 000
Duration: 3 years
Countries: The Netherlands, Germany, Belgium and Israel
Disease: Leukaemia and lymphoma
Status: Ongoing



A special registry to keep track of wonders and failures to build a better future

Today, when a child with cancer runs out of standard treatment options, they will seek treatment in the framework of a clinical trial in the hope to cure or at least to extend their life.

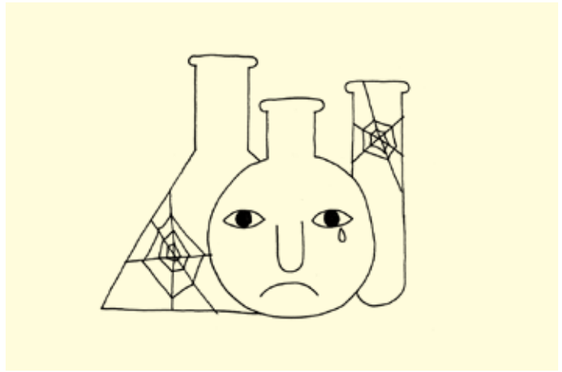
In the framework of a clinical trial, all the data about the effect of the tested drug are recorded with the specific intent to determine whether the tested drug is effective, and its toxicity is acceptable. Unfortunately, today, there are not enough relevant clinical trials for most of the children for which the current treatments are not effective.

Often, as a result, those children with cancer will be treated with a novel drug off-label, in the framework of a compassionate use or medical need programme. In such a case, the clinical data of the patients are lost, when in fact we would need to detect unnecessary toxicity or remarkable efficacy.

This is exactly what the SACHA international registry will do: collect real-life data about innovative therapies administered outside clinical trials to children, adolescents, and young adults with paediatric malignancies. These real-life data will help to: 1) recommend the halt of the prescription of the drugs that show to be ineffective or have an unacceptable toxicity, 2) support the development of paediatric clinical trials when a drug seems efficient.

SACHA International plans to include 500 patients per year over three years in several European countries, as well as Australia and New Zealand.

Financed: €846 000
Duration: 3 years
Countries: France, Italy, Spain, UK, The Netherlands, Ireland, Belgium, Austria, Denmark (Australia and New Zealand not funded by KickCancer)
Disease: All cancer types
Status: Ongoing



1.1. Research Projects

Naughty immature neuroblastoma cancer cells in check thanks to a new drug

It was recently demonstrated that **neuroblastoma** cells in the relapsed patients responding to treatment and those in the patients not responding to treatments were different.

In the patients not responding to treatments, it was discovered that the cells causing the relapses resemble immature cells type.

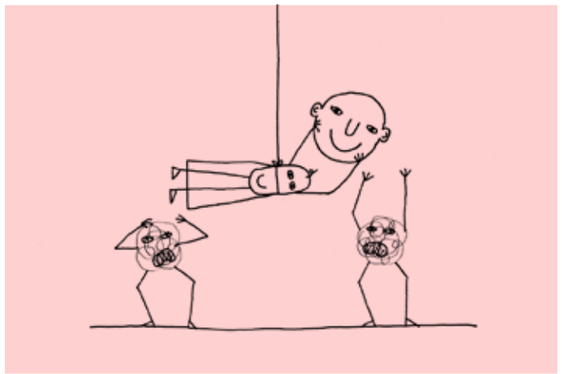
A drug that could kill those immature neuroblastoma cells would probably help those patients. One was previously discovered but unfortunately, it was not suitable for patients.

This project aims to test a new generation of that class of drug on a mouse to see if it can inhibit relapses.

In parallel, the project will aim at enabling us to detect the presence of immature tumour cells in human neuroblastoma tumours.

This project will as a result deliver all information required to decide whether to test this new drug in the framework of a clinical trial.

Financed: €400 000
Duration: 2 years
Countries: The Netherlands and Germany
Disease: Neuroblastoma
Status: Ongoing



Tiny patients with leukaemia but big shot to help them achieve a cure

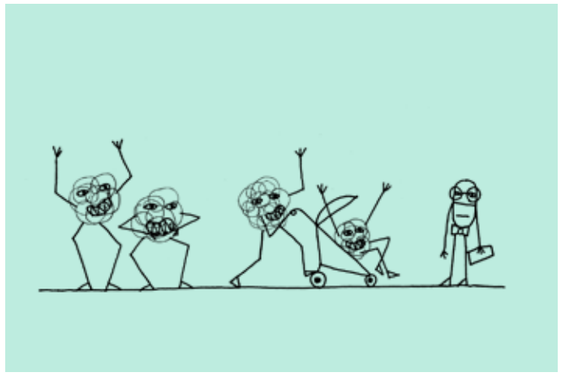
Acute lymphoblastic **leukaemia** (ALL) is the most common type of blood cancer. Today, about 90% of the children with ALL will survive. Unfortunately, this is not true for infants, i.e., children under 1 year of age.

This project pursues two objectives. First, it aims at understanding the mechanisms which make infant ALL so aggressive. It has already been demonstrated that most of the babies diagnosed with ALL carry a leukaemia-specific mutation in the MLL gene. Understanding the MLL gene is thus the key to better treatments.

Second, it will attempt to identify new treatment options by targeting these mechanisms and providing evidence to show that these newly identified treatments could be efficient.

The findings of this project will be discussed with the clinical trial groups that set up clinical studies in ALL.

Financed: €492 000
Duration: 2 years
Countries: The Netherlands, United Kingdom, Italy, and Spain
Disease: Acute lymphoblastic leukaemia
Status: Ongoing



1.1. Research Projects

24/7 monitoring tools to track myeloid leukaemia cells and target its cells with acute precision!

Today, only 60% of the patients with AML achieve remission despite very toxic therapies causing severe long-term effects for survivors.

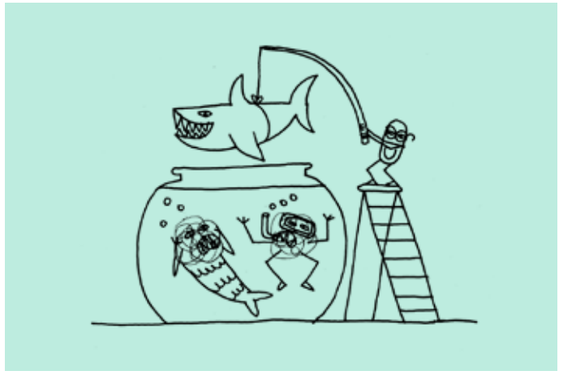
In the field of ALL, treatments were improved thanks to the development of highly sensitive **genomic technologies** to monitor the response of leukaemia to therapy.

In paediatric AML, one of the big challenges is the lack of similar highly sensitive methodologies.

This project proposes a novel genomic based methodology to identify response to therapy and to characterise the leukaemia cells that remain resistant to therapy. This could also lead to identification of novel drugs that may beat this resistance.

The development of the monitoring tools proposed by this project will hopefully lead to a precise adjustment of therapy for each child with AML and, consequently, to improve their chances to cure..

Financed: €500 000
Duration: 2 years
Country: Israel
Disease: Acute myeloid leukaemia
Status: Ongoing



Cloning or twinning: new methods to eradicate neuroblastoma!

An international team of computer scientists, biologists, and clinicians will collaborate to build computer models of patients (Digital Twins), which will allow the design of personalised therapies that are more efficient and less toxic than the current therapies.

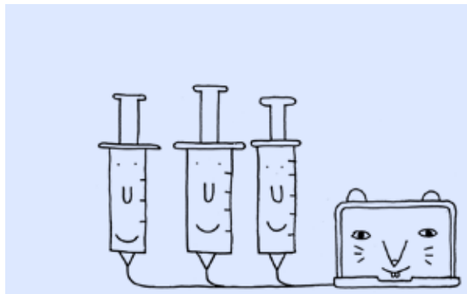
The team will start by building “DigiTwins” of mouse models with **neuroblastoma** by using advanced computational methods to combine these molecular data and constructing the Digital Twin models.

Every neuroblastoma mouse will have a corresponding DigiTwin computer model, which can be used to try out different treatments virtually on the computer so that the best possible individual treatment can be identified. These treatments then will be tested in the mice for comparison purposes.

Once the accuracy of the DigiTwin models in mice is ascertained, it will be translated to humans. The accuracy of these human DigiTwin models will be evaluated against the treatment outcomes of these patients.

The final objective of DigiTwins project is to pave the way for future clinical studies, where DigiTwins can provide better and more personalised treatments for neuroblastoma patients.

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



A global clinical trial to get rid of lymphoma

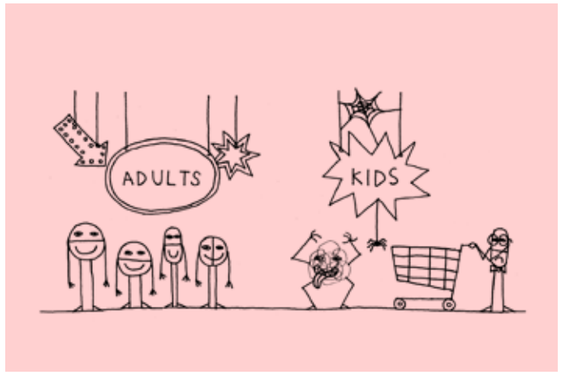
Despite intensive treatments, young patients with non-Hodgkin’s B-cell **lymphoma** (LNHB) who relapse or do not respond to treatments (refractory disease) are below 30%.

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: 3 years
Countries: UK, France, Italy, Germany, Netherlands, USA, Canada, Australia, and New Zealand
Disease: Lymphoma
Status: Ongoing



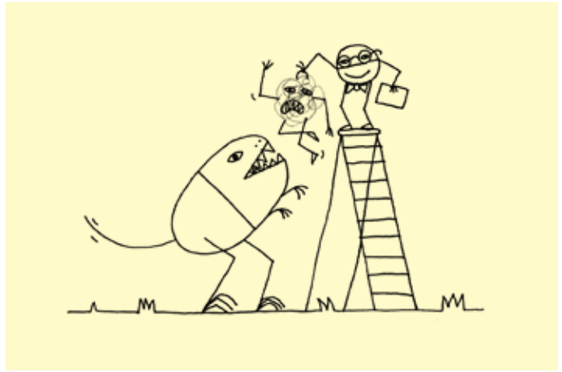
A clinical trial to break new ground in sarcoma treatment

The standard treatment for **Ewing 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 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: 3 years
Countries: France, UK, Italy, Spain, and the Netherlands
Diseases: Sarcoma
Status: Ongoing



1.1. Research Projects

A winning combo to exterminate medulloblastoma

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

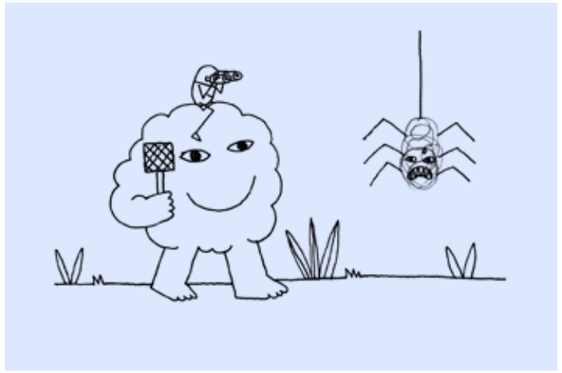
The translational research project “CARBEMED” aims at identifying a highly innovative treatment strategy that would combine two **immunotherapy** techniques:

- 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.

Experimental work only started in October 2022. Four medulloblastoma mouse models are now being investigated and awaiting results.

Financed: €499 000
Duration: 3 years
Country: United Kingdom
Disease: Medulloblastoma
Status: Ongoing



Overcoming treatment resistance in neuroblastoma

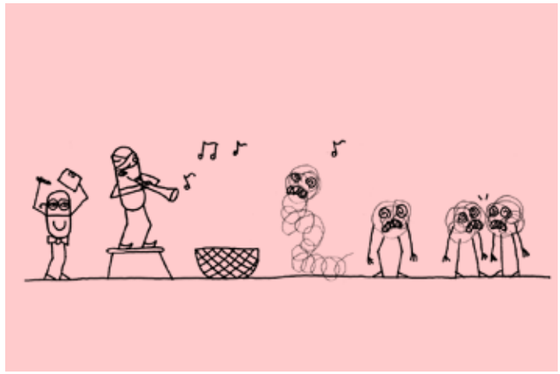
The survival rate of children with high-risk **neuroblastoma** whose tumour has an alteration in the “ALK” are very low.

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.

The project could only start later in 2022.

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



Improving our understanding of the mechanisms of resistance in neuroblastoma

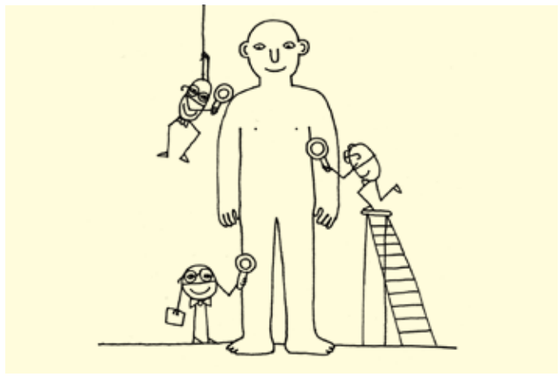
Despite intensive treatment, more than one in two patients with neuroblastoma relapse after frontline treatment and the chances of survival for these patients are below 10%.

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 00
Duration: 3 years
Countries: Spain, France, and the United Kingdom
Disease: Neuroblastoma
Status: Ongoing



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% of the 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.

Financed: €585 000
Duration: 3 years
Countries: France, Italy, the Netherlands, and Germany
Disease: High grade glioma
Status: Almost completed

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.

The project started in May 2021 and is expected to be completed in the course of 2024.
The project gathered a cohort of more than 200 patients and secured their genetic materials. The genetic sequencing as well as epigenetic and transcriptomic analysis are currently ongoing.

Several research findings were already published.

Financed: €500 000
Duration: 3 years
Countries: Austria and Germany
Disease: Brain tumours
Status: Almost completed

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

Many children with acute myeloid **leukaemia**'s (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.

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

Epigenetics for rhabdoid tumours

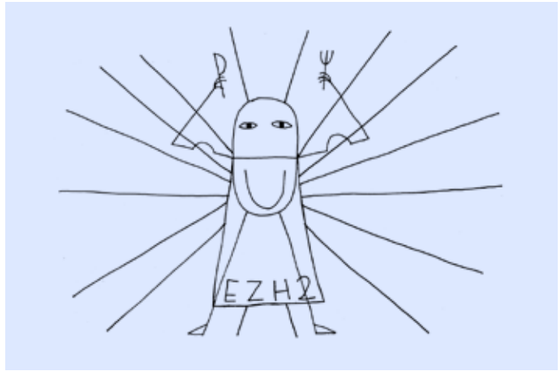
Survival rate for the patients with a **rhabdoid tumour** is under 50% and those surviving will have to go on with their life with oftentimes severe long-term side effects caused by their treatment.

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 **epigenetic** 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 epigenetic 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.

Financed: €500 00
Duration: 3 years
Countries: France and Germany
Disease: Rhabdoid tumour
Status: Ongoing



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.

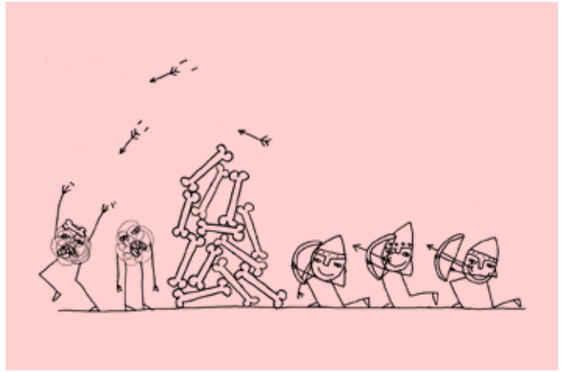
However, to this day, it has not been possible to replicate this success in patients with solid tumours like osteosarcomas. This is mainly due to the barrier posed by the hostile microenvironment surrounding the tumour. This barrier prevents the migration of white blood cells and diminishes their capacity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

Financed: €500 000
Duration: 3 years
Countries: Spain, France, Norway
Disease: Osteosarcoma
Status: Ongoing



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.

Financed: €500 000
Duration: 4 years
Countries: Belgium, United Kingdom
Disease: Neuroblastoma
Status: Ongoing

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.

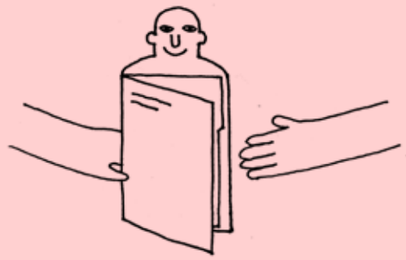
Besides, in Belgium, there is neither an organised specific long-term follow-up plan adapted to their medical history nor a specific reimbursement for such follow-up consultations.

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: €344 500
Duration: 4 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, United Kingdom, 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 seven for the first time in children. The trial offers seven recruiting therapeutic arms. Three new treatment arms opened in 2023. As of December 2023, 254 patients had been enrolled in this study through 19 hospitals.

Financed: €413 500
Duration: 4 years
Countries: France, the Netherlands, United Kingdom, Spain, Italy, Denmark
Diseases: 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**.

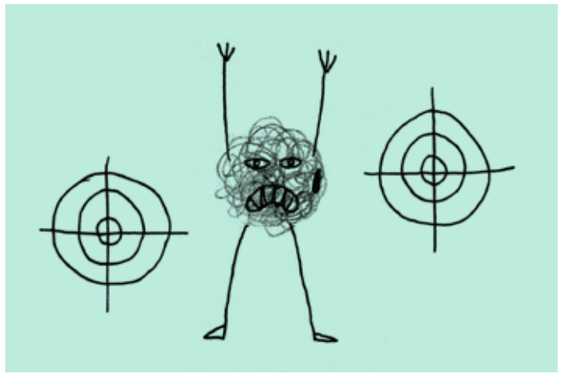
The clinical trial is taking place in six French hospitals and in three in Belgium (Ghent, Leuven and Brussels / Saint-Luc). It is open to patients with a solid tumour who do not respond to standard treatments or who are in relapse.

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).

Financed: €150 000
Duration: 6 years
Countries: France, Belgium
Disease: Solid tumours
Status: Ongoing since 2018



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.

The final results of this programme will be communicated once the target number of patients of 600 has been reached and completely analysed.

Financed: €200 000
Duration: 8 years
Country: France
Diseases: All 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 stakeholders 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. Each type of paediatric cancer is rare; some of them are extremely rare (occurrence of a couple of cases a year in Belgium… to one case every five year).

Research must be conducted at an international level to be effective and to deliver as fast as possible. This is why KickCancer was so keen to initiate a European programme: FIGHT KIDS CANCER.

FIGHT KIDS CANCER is a joint initiative founded by KickCancer with Imagine for Margo (France) and the Kriibskrank Kanner Foundation (Luxembourg). CRIS Cancer Foundation (Spain) and KiKa (the Netherlands), which had co-funded projects with us ad hoc in 2022, joined the initiative structurally in 2023, which increases our long-term capacity to fund research.

It aims 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.

For its fourth call for projects (2023), FIGHT KIDS CANCER led to the selection of 9 research projects for a total amount of 4,3 million euros. This came as a frustration as our team of five funding organisations disposed of 2 million euros in excess funds for research.

It was a difficult realisation for the five funding organisations as we did not feel satisfied that all research needs had been fulfilled after this fourth call for projects. On the contrary, we felt that many disease areas were completely under-served. After several brainstorming sessions, we decided to set up a new funding opportunity under the banner of FIGHT KIDS CANCER, to attract more young and talented researchers to the field of paediatric oncology: one innovation grant.

Unlike funding for a research project, where the applicant must submit a detailed budget and a clear description of their research plan, an innovation award is a funding opportunity which promotes thinking outside the box, true innovation, excellent quality of the science and potential for clinical impact. Funds are not "earmarked" to a given action or purchase and the grantee is free to use as they think it fits for their overall research endeavour: hiring staff for their lab, investing in equipment…

One well-renown US-based organisation, the St. Baldrick's Foundation, had already organised similar funding opportunities and had expertise in the organisation of such a selection process. In no time, we decided to partner with them to set up a joint award: FIGHT KIDS CANCER would fund it, and they would provide the back office to select the best applications.

The request for proposals was issued in November 2023 and we selected one outstanding researcher in April 2024, Mrs Sophie Postel-Vinay.

You will find above the projects co-funded by KickCancer. In 2020, 2021, 2022 and 2023 our FIGHT KIDS CANCER calls for projects have resulted in a selection, by independent international experts of 30 projects for a total amount of 18,2 million euros, out of which 21 projects, for 3 million euros are financed by KickCancer (please find the projects described above).

Based on the analysis of the projects funded during those first four years, we realised that there were too few projects aiming at disease areas with significant unmet medical needs, i.e., the deadliest types of paediatric cancers: brain tumours and sarcomas.

This is the reason why FIGHT KIDS CANCER decided to launch two calls exclusively dedicated to those disease areas. The first one, on brain tumours, will be concluded in 2024. The second one, on sarcomas, will be concluded in 2026. In 2025, the call will be "disease agnostic" again, to ensure that all children with cancer remain served by FIGHT KIDS CANCER. With these two exclusive calls, we aim at fostering a new interest from the research community in these two disease areas.

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.

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**.

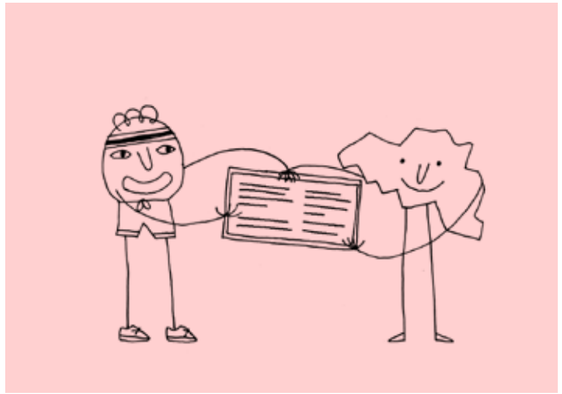
The protocols for these late-stage clinical trials are designed in the framework of SIOPE's (Société International d'Oncologie Pédiatrique Europe or the European Society for Paediatric Haemato-Oncology) disease-specific collaborative groups where specialists of one disease meet and jointly define the 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 financing the work of its coordination cell on an annual basis (for 2023, €125 000). 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.

Since the collaboration agreement signed in 2021, KickCancer also started funding the Belgian part of the pan-European late-phase clinical trials.

In 2023, we supported the funding of one clinical trial in the field of myeloid leukaemia's for an amount of € 65 000.



European Institutions

A new colleague to strengthen the European affairs team

In 2023, KickCancer welcomed Teresa Pais in their offices, a new colleague from Childhood Cancer International – Europe (CCI Europe), to strengthen the team responsible for European affairs. The European health agenda gains in momentum and reinforcing the team was a very timely move to ensure our presence on all fronts. Teresa is a CCI Europe employee working together with Delphine and Marine. Delphine is indeed leading the CCI Europe's European Affairs' Pillar.

Hot topic: the revision of the legislation on medicines for children and rare diseases

Together with peer European patients' and doctors' organisations, KickCancer has been advocating a more favourable pharmaceutical legislation in Europe ever since its foundation.

Building on what had been achieved in 2021 and 2022 regarding the **revision of the Regulations on Medicines for children and rare diseases**, we continued to advocate, throughout 2023, a revision that puts the unmet medical needs of young cancer patients at the centre of a European strategy for drugs development.

This dossier kept us busy throughout 2023: the European Commission published in April their proposal for the revision of the EU Pharmaceutical legislation, which includes provisions on rare and paediatric diseases.

During the summer of 2023, our EU affairs team analysed the proposal of the Commission with quite some satisfaction: most of our asks had been included in their proposal, except for a few minor items about which we drafted a statement proposing minor amendments.

These are the main demands we have been advocating for years and that the European Commission addressed in their proposal:

1. It will become mandatory for pharmaceutical companies to submit a Paediatric Investigation Plan for new medicines originally developed for an adult cancer (even when the disease does not arise in children) when the mechanism of action of the new drug is relevant for a type of paediatric cancer.

2. If academia demonstrates that a treatment is beneficial for a patients' population, they can submit the data to the European Medicines Agency for review. If the EMA finds the data compelling, they can mandate the market authorisation holder to put that new use of their medicine on label. In other words, this future provision will help reduce the events of off-label use of medicines and ultimately facilitate reimbursement of medicines at national level.

1.2. Advocacy

Two of our asks have not been met: dedicated incentives to stimulate the development of medicines aiming specifically at paediatric cancers are lacking, while we are still missing effective measures to ensure equal access to essential anti-cancer medicines for children across the European Union.

While the proposal was in debate at the European Parliament, we met with several Members of the European Parliament throughout 2023 to advocate our point of view on the Commission's proposal.

In 2024, the proposal will be passed on to the Council and we will need to plan meetings with the Member States' Permanent Representations (in particular, their "health attaché") to raise their awareness on the needs of young patients with cancer.

Paediatric cancer in the spotlight

Thanks to Kickcancer's involvement in advocacy work at the European level, a number of projects relating to paediatric cancer have been launched since 2021 under Europe's Beating Cancer Plan and the EU Mission on Cancer, as part of the Horizon Europe Programme.

CCI Europe plays a role in some of these projects:

- We pushed the topic of survivorship, which led to the creation of the EU Network of Youth Cancer Survivors (EU-CAYAS-NET) which aims to develop a platform to improve links amongst individuals, patients, children, adolescents and young adults cancer survivors, caregivers, researchers, and social and health professionals active in cancer prevention and care across the Union.
- CCI Europe represents childhood cancer patients in the UNCAN.eu project, an initiative that aims to understand cancer and its mechanisms better to improve cancer prevention, early diagnosis and treatment.
- The project UNICA4EU aims at building an ecosystem that will facilitate a wider use of artificial intelligence to paediatric cancers in the next ten years, positioning Europe as the worldwide benchmark in this field.

Upcoming European elections

Ahead of the European elections in 2024, CCI Europe, in collaboration with SIOPE, launched a European Elections Manifesto featuring the priorities of the childhood cancer community for the next mandate (2024-2029).

We called on Members of the Parliament to support us by facilitating the adoption of essential regulations for young patients with cancer and by maintaining a significant budget for health and more specifically for childhood cancer.

The Patients' Voice

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

This Committee structurally empowers the voice of young patients and their parents and thereby contributes 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 to mirror their needs and, ultimately, to improve research or the regulatory environment.
- **Patient advocates** who ambition to participate more actively. Our patient advocates were selected after a recruitment phase, and they completed a specific training conceived in collaboration with the PEC (Patient Expert Center). 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.

In 2023, our Patient Committee was joined by **12 new "patient advocates"**. They joined the 30 advocates who were already certified and have been active in several internal and external projects since.

MY COMPANION Support kit is a fantastic example of what our Patients' Committee has achieved.

MY COMPANION Support kit: a brilliant tool created by patients for patients!

You might think that MY COMPANION is a toolbox... In fact, it's a practical tool designed to help families navigate the cancer storm. It offers practical and medical support from diagnosis throughout the treatment process. Developed with six of our patient advocates, the kit has been designed to meet the practical needs they have identified during their own or their child's cancer journey. The result is a compilation of useful information, helpful advice and tools brought together.

It includes, for example, a comprehensive cancer glossary, examples of relevant questions to ask at consultations during the different stages of treatment, and 'real-life' advice and tips on how to make the most out of the new daily family life.

The kit also includes a folder to organise the documents received in hospital, a notebook to prepare for consultations and take notes, and a calendar to monitor and anticipate the effects of treatment. The aim? To make medical information, which is often complex, more accessible to newly diagnosed patients. The kit also includes fun goodies to enable parents and their children to personalise their kit.

1.2. Advocacy

KickCancer's annual patients conference

A. Patients Conference 2023 on adolescents and young adults

On May 26th, 2023, KickCancer organised its **second annual patients conference with the aim of improving care and research for Adolescents and Young Adults (AYAs) with cancer**.

The purpose of the conference was to draw attention on the specific needs of AYAs, with an eye on improving their chances to survive and their quality of life during and after treatment.

The conference brought all the key stakeholders together: patients, doctors, psychologists, care coordinators, social workers, Belgian authorities, patients and organisations working in the field.

The conference emphasised the need for a specific care journey, which does take the peculiar psycho-social needs of young adults into account, that is to say: fertility preservation, access to a tailor-made treatment plan and to clinical trials.

What happened after the conference?

In November 2023, a convention was established between six reference hospitals (the six Belgian university hospitals) and the NIHDI (RIZIV/INAMI). This agreement allocates a budget to set up a dedicated AYA team in each reference centre and provides funding for trainings on AYA care, first in the reference hospitals, and at a later stage, in satellite hospitals.

Since then, KickCancer has been working closely with its patient experts, Kom op tegen Kanker (Stand up against Cancer) and the Foundation against Cancer to contribute to the development and implementation of this agreement and a harmonised AYA care policy.

B. Conference of 2022 on the reimbursement of drugs

What did we achieve thanks to the 2022 conference on the reimbursement of drugs?

In 2022, KickCancer drew the authorities' attention to the fact that children with cancer often did not benefit from an easy access to drugs that are "off-label". These drugs, despite being part of standard treatment guidelines, were not reimbursed. This conference marked the kick-off of our advocacy campaign for the reimbursement of these drugs.

KickCancer's hard work did pay off, as since the 1st of January 2024, 50 standard of care drugs used for children with cancer started being reimbursed. Besides, a structural solution for future drugs is in place in the event they would also become "standard of care".

At the time of publication of this annual report, KickCancer is preparing the 3rd edition of its patients' conference, which will focus on access to and the funding of clinical trials in Belgium.

Winners' Cup

Since 2017, the football club Inter Milan has been organising a football tournament where teams of adolescents and young adults who experienced cancer compete with one another. For its third edition in 2019, the tournament extended to Europe, and Belgium took part for the very first time. During the pandemic, this initiative was put on hold, but in 2023 it resumed with six European teams (Belgium, France, Germany, Greece, the Netherlands and Spain) and ten Italian teams.

Twelve young Belgians decided to wear the colours of their country under the guidance of KickCancer. They attended a warm-up training session before their departure to get to know each other (and do a bit of sport!) and proudly wore the national football uniform generously donated by the RBFA (Royal Belgian Football Association).

We could tell you the results of the tournament, but that is not what really matters.

The tournament was organised to **draw attention to the specific situation of adolescents and young adults**. They are stuck between two phases in life (childhood and adulthood) and need dedicated research and care centres specifically designed to meet their particular needs.

It is also crucial for these young patients who are developing their identity to be able to meet fellow survivors whom they can share their experiences with. The Winners' Cup is a wonderful opportunity to highlight the importance of sport as a tool for social inclusion as well as emotional and mental support for these young people.

Art Brussels

In April 2023 we organised the first edition of The KickCancer Collection within the contemporary art fair Art Brussels. What a success it was!

All gallerists were asked to invite the artists they represent to create one or more post-card sized artworks to show everyone what “Small art with a big heart” looks like.

The outcome? A massive wall decorated with small artworks that were sold anonymously (signed on the back) for the flat rate of €400 to the benefit of KickCancer. Visitors had to choose their favourite artwork and buy it before they could discover its author.

Thanks to the enthusiasm of the artists, gallerists, art collectors, media and team Art Brussels… we did repeat the action and showed “The art of supporting by surprising” again during Art Brussels 2024.

87
PARTICIPATING GALLERIES

216
PARTICIPATING ARTISTS

33
MEDIA MENTIONS

274
ARTWORKS SOLD

109 600
EUROS FUNDRAISED

RUN TO KICK

KickCancer’s sixth edition of RUN TO KICK, our family charity race, took place on September 24th, 2023. We proudly gathered more than 2400 runners who raised together the fantastic amount of 1 207 646 euros (on D-Day).

Our godfather Niels Destadsbader gave the official starting shot to the participants who ran or walked 2, 5 or 10 km by the Atomium.
It was a genuine highlight of the past year, in which we felt togetherness and solidarity. Icing on the cake was (again) the beautiful weather, the sun was shining as were all the runners, friends, colleagues, and families.

Year after year RUN TO KICK grows and offers a whole-day programme with entertainment, in a village with delicious food trucks, bars with craft drinks and even a KickCancer shop. In 2023, for the first time, we hosted live concerts by Rori, Hyphen Hyphen, Berre and Pierre de Maere thanks to our partner NRJ.

In the meantime, our priority remains the creation of a super warm atmosphere. The joy of being together was palpable and so was the emotion… We were very happy to see that the clear winner of the race was solidarity with families with a child with cancer.

In 2023, we have reached the record amount of 1 271 003 euros (end of October). Thanks to our sponsors who finance RUN TO KICK’s organisation costs, among which NRJ, the National Lottery and Delhaize are the largest, we were able to invest 100% of this amount in 9 innovative FIGHT KIDS CANCER research projects.
In 2024 we are aiming for… 1,5 million (you can do it again!). We will welcome you to our cool and happy event.

Register now on RUNTOKICK.BE for the charity race of the year on September 29th, 2024. It will be fun, moving and above all full of joy. And you will contribute to financing the best innovative research projects. In 2024, we will focus our research endeavour on brain tumours, the deadliest types of paediatric cancers.

2 402
RUNNERS

16 700
DONORS

1,27 M
EUROS FUNDRAISED

65
MEDIA MENTIONS

Super bien encadrée, des stands supers qualitatifs, une ambiance familiale pleine d'attention pour les enfants !

The Kids' Corner at RUN TO KICK!

Ideale omkadering: opwarming, optredens... Je hebt wel gesport, maar errond valt ook zoveel meer te beleven.

Tout était parfait, je reviendrai d'office !

The joyful and dynamic atmosphere in which we all work together towards one single goal: improving research to help save children with cancer and reduce the long-term effects of today's heavy treatments.

De samenhorigheid en positieve vibes ondanks de vele schrijnende verhalen.

1.4. Raising awareness

Media

KickCancer benefited from massive media attention on our key activities organised throughout the year: International Childhood Cancer Day with the launch of MY COMPANION (February), the first edition of The KickCancer Collection at Art Brussels (April), a delicious action with 19.000 mini eclairs (May), our second Patients Conference on an important subject matter (the need for specific expertise and care for AYAs) (June), the press campaign about RUN TO KICK (from July until the end of September).

We ended the year with very positive communication about the outcome of our work to get Off-label medication reimbursed from the 1st of January 2024 (December).

In 2023 we worked with the professional Public Relation agency oSérieux to ensure our media presence while conveying the right messages about paediatric cancers.

18

TELEVISION
APPEARANCES

190

ARTICLES IN
THE WRITTEN OR DIGITAL PRESS

11

RADIO
APPEARANCES

Awareness

Curing more children with cancer and making sure that long-term side effects caused by the current treatments be reduced requires that we understand and acknowledge that there is a problem and that we must do better.

This is the reason why KickCancer invests in awareness so that everyone understands the specificities of paediatric cancer and the solutions that KickCancer proposes to put in place.

You can also contribute to increase paediatric cancer's visibility by registering for RUN TO KICK. While you solicit donations from your friends and family, you contribute to spreading our important message: children with cancer need our support!

The National Lottery

Since 2019, the National Lottery has been a loyal partner of KickCancer. We were able to carry out numerous projects thanks to the support of the National Lottery and its players: awareness campaigns on the topic of childhood cancer and support for our actions such as the organisation of the Eclair Day or RUN TO KICK. This paved the way for a strengthening of this partnership to continue this collaboration in 2023 and 2024. One thing is for sure: the National Lottery is much more than just games.

Thank you for being part of our family, kickers!

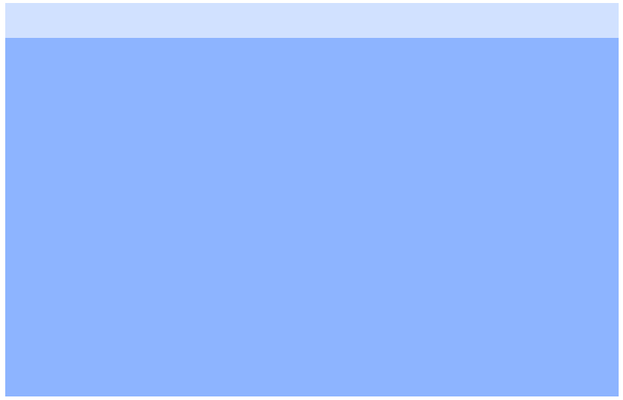
2. Financial report

In this section, for the sake of legibility, we have combined KickCancer's revenues generated through the "Fund of the Friends of the KickCancer Foundation" within the King Baudouin Foundation (donations with tax deductibility only), and those generated through the KickCancer Foundation itself (donations without tax deductibility, sponsoring and registrations or sales).

All spendings are funnelled through the KickCancer Foundation.

Sources of funds

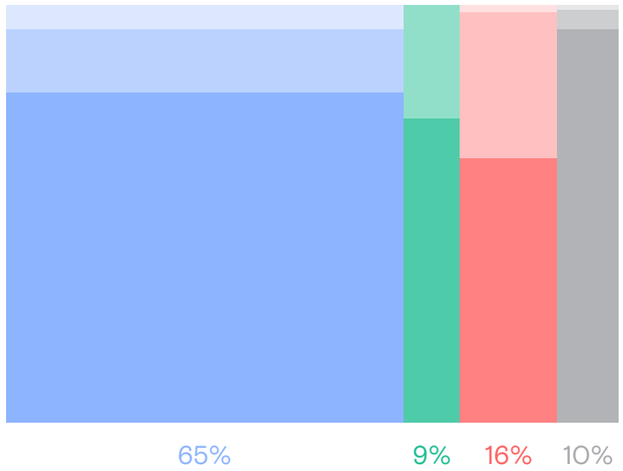
TOTAL **3 007 974**



Registrations & sponsoring	265 133
Donations	2 742 840

Usage of funds

TOTAL **3 007 974**



PROJECTS	**1 960 723**
Advocacy	112 315
Patients empowerment	298 727
Research projects	1 549 681
AWARENESS	**267 227**
Awareness campaign & material	72 903
Organisation of events	194 324
ADMINISTRATION	**488 491**
Investments	8 508
Administrative costs	170 868
Salaries	309 115
RESERVE	**291 532**
BSPHO reserve	2 000
Operating expenses reserve	15 000
Available reserve	274 532

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

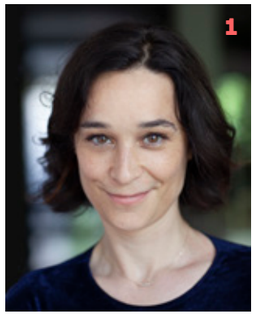
7 **Deborah Janssens**
Lawyer partner at Freshfields Bruckhaus Deringer

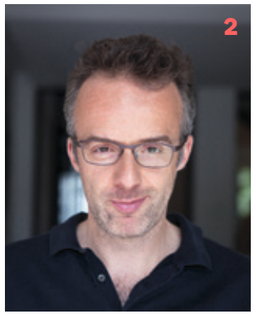
8 **Christophe De Vusser**
Director and CEO at Bain & Company

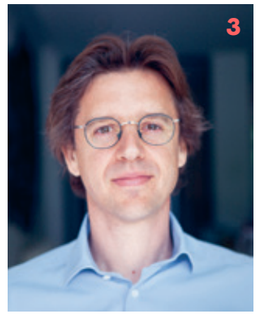
9 **Frédéric Rouvez**
Founder and Managing Director of Exki

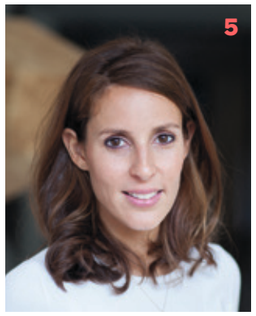
10 **Jo Van Biesbroeck**
Director at Telenet SFI (Lux) and Matexi

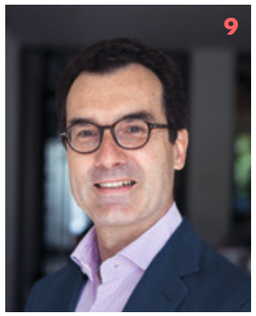
11 **An Winters**
Senior Client partner at Korn Ferry











3.2. Permanent team

The permanent team consists of ten people, Delphine and nine other kickers with superpowers:

1 **Annelies Boddez**
Kicker-in-Communication

2 **Fiona Debève**
Junior Kicker-in-Efficiency

3 **Nathalie De Clercq**
Kicker-in-Marketing

4 **Tille Geerkens**
Junior Kicker-in-Organisation

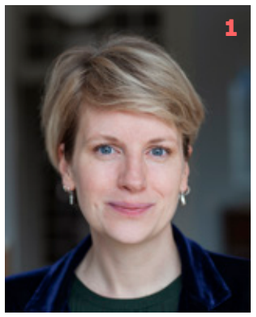
5 **Alice Gerbaux**
Kicker-in-Empowerment

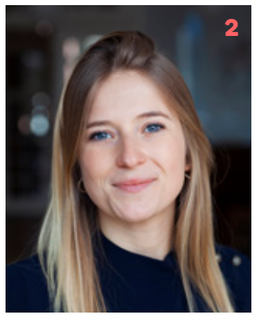
6 **Marine Gouders**
Junior Kicker-in-Advocacy

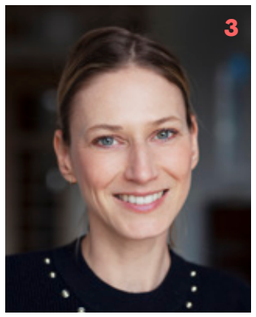
7 **Valentine Janssen**
Kicker-in-Operations

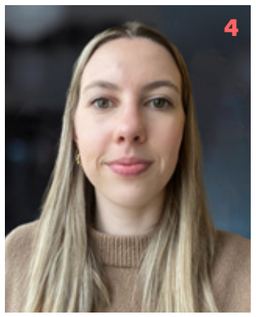
8 **Eric Peeters**
Kicker-in-Administration

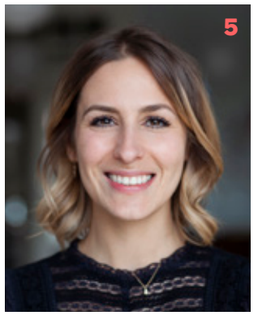
9 **Caroline Stals**
Kicker-in-Engagement

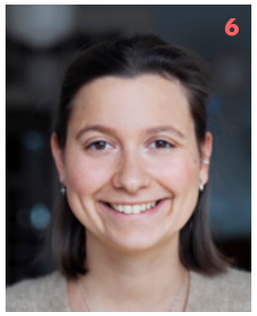


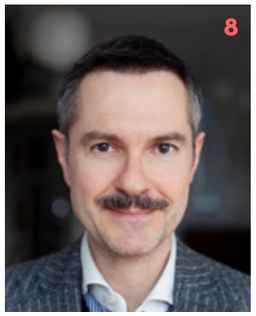


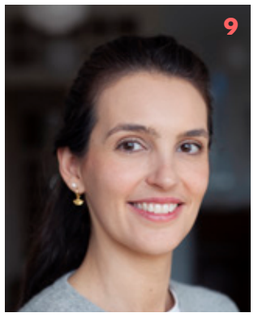












kickcancer.org

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

To make a donation

You can make an online donation or you can make a donation via bank transfer.

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

Any donation of €40 or more, made in one or several payments over the course of one tax year, is tax deductible up to 45% in Belgium.

The Foundation accepts dual legacies and can help you put them in place. 80% of your donations will directly fund research or will go to our activities to defend children with cancer, while than 20% will be used for our fundraising and administration.

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

Recurring Donations

It is possible to support KickCancer in the long run. All you have to do is make a recurring donation through your online banking platform or app.

KickCancer loves long-term supporters: they offer us the comfort of a long-term perspective. We can count on their support without spending a minute on fundraising or a dime on marketing — it is the safest way to make sure that we focus on our core mission: cure every child with cancer.

If you donate €40 or more over the course of one tax year, you will receive a tax certificate that will entitle you to a tax saving of 45% of the amount you donated (e.g for €40 donated, the final cost is only €22).

Start your monthly donation on KickCancer's webpage in two clicks: here. Or use our banking coordinates to set up a recurring donation:

Beneficiary: King Baudouin Foundation
Bank account: BE10 0000 0000 0404
BIC: BPOTBEB1
Communication: 016/1960/00070

CURE. DON'T CRY.

kickcancer

Contact
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