I’m too small to cure, are you too big to care?
Dear KickCancer supporter,

We are later than usual for this third annual report and we do hope the wait contributed to arousing your curiosity — but we apologise for this. It has been an unusually busy start of the year for us, which means that hope for brighter days ahead is definitely on the way!

A few key metrics

- Almost 1.4 million euros raised over one year – and 4.3 million during the four first years
- 8 new research projects financed for 1 103 000 euros
- 750 runners participating in RUN TO KICK and 11 000 donors who supported KickCancer
- More than 90 articles in the written and digital press, 4 radio and 4 television appearances
- 15 people contributing to KickCancer’s success as employees, freelancers or volunteers
- 1 dream ambassador: the singer Angèle herself
- 12 000 éclairs sold give cancer a taste of its own medicine
- 5 contributions to European public consultations and 1 position paper on European cancer policies

The first lockdown hit all of us pretty hard but one of our hedges here at KickCancer is that we have been hit on the head before and resilience is our motto!
Isolation definitely had a sense of déjà-vu for families of cancer patients and the lockdown forced us to recyle this well-ingrained competence of making lemonade out of sour lemons...

We could only rejoice about the fact that health and solidarity became central topics and that the hard work of all health professionals gained a very well-deserved recognition.

We managed to turn RUN TO KICK into an online yet warm moment, making sure that our first call for European projects (FIGHT KIDS CANCER — more on this later) becomes a success.

We received the incredible support of the singer Angèle, who helped us turn this “plan B” into a magical moment, even if we missed you all dearly. Gui-Home also joined our crew to ensure that our kicking spirit was well represented.

In November, we also launched with Pierre Marcolini the worldwide première of Eclair Day, which rallied 50 bakeries and gourmets around a deliciously regressive pastry.

But do not worry: our mission in 2020 did not only consist in organising fun events to distract our supporters from the languishing atmosphere.

We worked hard and made some significant breakthroughs!

We delivered on our first FIGHT KIDS CANCER call. We selected 6 cutting-edge research projects on five different types of malignancies, all of which in great need of better treatments to improve survival and quality of life during and after treatment.

We launched our second call in October 2020 and selected 5 new projects that will be financed thanks to RUN TO KICK 2021. We were excited to witness the enthusiasm from the research community as the number of applications doubled over one year. Undoubtedly, the overall quality of the projects improved too, which made it excruciating to turn down certain applications.

It definitely reminds us of the great need for more sources of funding for research in paediatric oncology. RUN TO KICK needs to grow (register now!!!) and we need to convince other countries to organise a race too and join the FIGHT KIDS CANCER programme. In 2021, Italy will become the 4th country to run; we will work to recruit more candidates over time.

Our patients’ committee project was delayed because of the pandemic but the training could start early May 2021 with 20 motivated future expert patients, half parents, half patients.

We contributed very intensely to the European political agenda, which flourished in 2020 after a couple of very slow years... As a result, we worked on several major
initiatives around health: *Europe’s Beating Cancer Plan, the Pharma Strategy, the Cancer Mission*...

For 2021, we have two major ambitions. First of all, we started collaborating more tightly with the *Belgian Society of Paediatric Haematology Oncology (BSPHO)*. We want to structure a real partnership and further improve together the care to our community of patients.

Last but not least, we are very focused on the *European agenda*: a lot of initiatives are ongoing, all of which should really have a positive impact for young patients with cancer. We want to make sure this happens.

These ambitions will require funding and manpower — so sorry to say, but *we will need you in 2021 again* and the many years to come but we enjoy the ride on your side so much: we hope you do too!

**Delphine Heenen**  
Kicker-in-Chief
We want to cure every child’s cancer. Find new treatments, improve existing ones, and kick children’s cancer to send it far, far away forever and may it never come back!

1st cause of death by disease for children aged over 1 year
All paediatric cancers are rare, but some are very rare and receive very little scientific attention even if some of them have a very poor cure rate (below 50%). The situation will only improve if we finance more research about those high-risk cancers.

6,000 deaths in Europe / year

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

35,000 new cases in Europe / year

Innovation is lagging for children, and survival rate is stagnating
Interestingly, this happened while significant progress occurred in adult oncology. We must accelerate research for children!

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

Only 1 in 10 children who runs out of treatment options has access to an innovative clinical trial
When standard treatments no longer work, it is common practice to offer a patient running out of therapeutic options the opportunity to participate in a clinical trial — even if the efficacy of the treatment is not demonstrated yet. In paediatrics, this option is only an exception. We need more funds for academic research and a more favourable regulatory context so that new drugs can be discovered in paediatric oncology and that more clinical trials open for the benefit of children with cancer.

2/3 survivors suffer from long-term effects
Nowadays, anti-cancer treatments are heavy and leave survivors with severe long-term sequelae. Survivors represent about half a million people in Europe today. We must make sure that those long-term sequelae are either prevented or properly identified and treated or prevented.

Cognitive dysfunction (blindness, hearing loss)
Knee or hip replacement (major joints)
Amputation (foot, leg, hand...)
Organ removal (kidneys)
Coronary or artery disease
Cardiac failure
Secondary cancers
Post-traumatic stress disorders

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

Adolescents and Young Adults (AYAs) need proper care facilities
Being a “big child” in a paediatric ward or a “young buddy” in a cancer centre: this is how adolescents and young adults feel when they are diagnosed with cancer: they feel like they do not belong to where they are. It is not “just” a question of recognition: being treated in age-appropriate facilities has a direct impact on the quality of care, the patient’s ability to trust its treatment and even access to adapted or innovative treatments. We must help AYAs improve the quality of care and access to research too.
1. Activities report

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 re-injected into the patient’s body. T-cell transfer therapy may also be called adoptive cell therapy, adaptive immunotherapy, or immune cell therapy.

Diffuse intrinsic pontic gliomas (or DIPG)
A type of brain tumour for which there is currently no cure. Research for these brain tumours is direly needed.

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

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

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

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

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

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

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

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

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

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

Metronomic chemotherapies
Treatment in which low doses of anticancer drugs are given on a continuous or frequent, regular schedule (such as daily or weekly), usually over a long time. Metronomic chemotherapy causes less severe side effects than standard chemotherapy, can improve life expectancy and ensures a better quality of life during treatment.

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

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

Platform trial
A “platform trial” is a clinical trial with a single master protocol in which multiple treatments are evaluated simultaneously. Adaptive platform designs offer flexible features such as dropping treatments for futility (lack of efficiency), declaring one or more treatments superior, or adding new treatments to be tested during the course of a trial.

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

Rhabdomyosarcoma
A paediatric type of cancer that forms in soft tissue that can develop in several parts of the body (from head to toe). It is the most common soft tissue sarcoma in children.
1.1. Research Projects

KickCancer finances 14 research projects in the hope of improving treatments for children with cancer.

1.1.1. NEW RESEARCH PROJECTS

Long-term follow up of patients

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

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

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

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

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

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

- Provide each patient with a summary of the treatment received, relapse, secondary cancers, acute toxicity, 5-years survival.
- Advocate with the Minister of Health the set-up of a specific financing for such follow-up consultations.

The projects described under this section have been selected by independent experts in the framework of our European call for projects FIGHT KIDS CANCER. The financed amount indicated under each of those projects is the total amount required for the project, which is jointly financed by Imagine for Margo, the Foundation Krijtskranck Kanner and KickCancer.

**A very innovative clinical trial for brain tumours**

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

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

The hypothesis of the “AsiDNA Children” study is that, in children and adolescents with recurrent 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 project’s long-term objectives are to:

- 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

**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 found in other tumours such as glioblastoma, medulloblastoma, ependymoma... Those findings could also benefit those latter patients.

**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.

**FIGHT KIDS CANCER projects**

Financed: 203,000€
Duration: 1 year
Country: Belgium
Diseases: All types of cancer
Status: Ongoing

**POBCORN**

Financed: 498,000€
Duration: 2 years
Countries: Austria and Germany
Disease: Brain tumours
Status: Ongoing

**Follow-up project**

Financed: 580,000€
Duration: 2 years
Countries: France & United Kingdom
Disease: High grade glioma
Status: Ongoing

**ALARM3**

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

**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 SMARCBI. Since there is no other genetic mutation*, SMARCBI 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 “EpiT” 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 cell level, how human tumours evolve when engrafted.

*Characteristics of the tumour 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.

**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 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.

**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 models to evaluate the efficacy of “RRM2” that neuroblastoma cells rely on for sustained growth.

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**1.1.2. ONGOING PROJECTS**

**Improving our understanding of the resistance mechanisms of high risks cancers**

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

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

This project will allow for a better understanding of the avoidance and resistance mechanisms to the standard treatments. In conjunction with other ongoing projects, the results of this analysis will enable doctors to swiftly redirect patients towards the best therapeutic strategies.

As of 31 December 2020, 334 patients have been enrolled in the trial and analyses are now underway. This recruitment is in line with the target (800 patients in total). The objective is to recruit 120 new patients in 2021. The molecular and immunological analyses of the patients already recruited and the structuring of these analyses is underway. As the project is spread over six years, no results can be reported to date.

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Financed: 800 000€
Duration: 2 years
Countries: Belgium and United Kingdom
Disease: Neuroblastoma
Status: Ongoing

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Financed: 800 000€
Duration: 2 years
Countries: Belgium and United Kingdom
Disease: Neuroblastoma
Status: Ongoing
### 1.1. Research Projects

#### A clinical trial for refractory or relapsing solid tumours

This innovative clinical trial will test the combination of three classical metronomic chemotherapy 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.

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

#### E-SMART: an innovative pan-European clinical trial

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

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

This study initially opened in France in 2016 and has now been extended to the Netherlands, UK, Spain, Italy and soon Denmark. Since its opening, 14 treatment arms have been opened, which allowed to test 19 drugs in total (single agent or combination), including 7 for the first time in children. Three new treatment arms are currently in preparation. As of 20 May 2021, 169 patients have been enrolled in the study.

This project is coordinated through the ITCC network (Innovative Therapies for Children with Cancer) and is simultaneously funded by Imagine for Margo (France) and Fondation Kriibskrank Kanner (Luxembourg).

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

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

#### 11.3. CLOSED RESEARCH PROJECTS

### Two projects with ITCC

These two projects were selected in collaboration with the ITCC (Innovative Therapies for Children with Cancer), an organisation of leading hospitals in the field of paediatric cancer research, following a European call for projects.

#### Liquid Biopsies

For children with rhabdomyosarcoma, assessing response to treatment and whether they remain in remission requires regular imaging such as MRI (which requires anaesthesia for younger patients).

The aim of this study was to validate the usefulness of the liquid biopsy technique which would allow patients to be followed with simple blood tests instead of MRIs. This technique would also allow to improve the therapeutic follow-up of patients if resistance to treatment or relapse can be detected earlier, and lead to a swifter adaptation of the treatment.

This study validated the relevance of the concept of correlation between the amount of rhabdomyosarcoma specific DNA found in the blood and the quality of the response of said patients to their treatment.

Results of the study have supported the need to further collect plasma in the next international clinical trial for rhabdomyosarcoma patients – FaR-RMS (Frontline and Relapse – Rhabdomyosarcoma). Furthermore, Bayer is currently considering funding liquid biopsies in this new trial.

Financed: 150 000 €
Duration: 1 year
Countries: France & Germany
Disease: DIPG
Status: Closed

#### A better cure for an incurable brain tumour

Brain tumours are the main causes of mortality and morbidity of children, adolescents and young adults. Gliomas are the most frequent and the most fatal kind, among which the diffuse intrinsic pontine gliomas (or DIPG) represents the most severe form, universally incurable with hardly any patients surviving more than 2 years after diagnosis.

This project led to the identification of three distinct subroups of DIPG within what we used to think constituted one single group, thanks to an analysis of their differences at an epigenetic level.

These results will allow us to contemplate different targeted treatments for each sub-group, despite the fact that from a purely genetic point of view, they seemed to present the same genetic mutation.

This project has also produced raw data which, when analysed, will provide valuable information on the mechanisms underlying the initiation of this disease and will serve as a basis for the development of new therapeutic solutions.

Financed: 150 000 €
Duration: 1 year
Countries: France, UK, Italy, Spain, Switzerland & Netherlands
Disease: Rhabdomyosarcoma
Status: Closed
A data manager for a European organisation of doctors

By paying the salary of a data manager for 3 years, we enabled the EPSSG, the European association of paediatric oncologists specialised in soft tissue sarcoma, to analyse data from a completed clinical trial on rhabdomyosarcoma* from new angles.

The goal was to analyse the combination of factors currently used to define the risk group stratification system and to determine whether another classification method should be used to improve patient treatments on the basis of their risk group. This study also advocates an international standardisation of the classification method.

A total of 2,138 patients were included in the study. This project demonstrated that replacing one of the factors resulted in a stratification that better identified patients at higher risk of relapse and made it possible to build a new stratification model.

Specifically, in the new treatment protocol, a first category of children was transferred from the “high risk” to the “standard” risk group, which justifies the use of lighter treatments in the hope of reducing the long-term side effects caused by the treatments. On the other hand, a second category of patients was transferred to a higher risk group and will receive a heavier treatment in the hope of improving their survival chances. This new stratification will be further validated in the currently ongoing study on rhabdomyosarcoma.

This project also led to the signature of an international Memorandum of Understanding between Europe, the USA, Canada with the aim to merge their existing databases and define harmonised guidelines for the registration of new patients consistently to improve our understanding of the disease.

Financed: 93 000 €
Duration: 3 years
Countries: Europe
Disease: Rhabdomyosarcoma
Status: Closed
1.2. Advocacy

KickCancer’s second line of action to improve treatments available for children with cancer is to connect with all the players in the field (doctors, researchers, regulatory authorities, pharmaceutical industry and other philanthropic organisations active in the field of cancer). Understanding and listening to the players’ constraints is crucial to create a more favourable regulatory and environmental climate 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 made and financed.

Paediatric cancers are a group of cancers, which are all rare cancers — even those with the highest prevalence in children.

In order to be effective, research needs to happen at an international level. This is why KickCancer was so keen to initiate a European programme: FIGHT KIDS CANCER.

**FIGHT KIDS CANCER** is a joint initiative of KickCancer, Imagine for Margo (France) and the Kriibskrank Kanner Foundation (Luxembourg) aiming at promoting the most innovative treatments through collaboration and funding at the European level of research against childhood cancer. FIGHT KIDS CANCER calls for and oversees the submission of annual projects.

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

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

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

In 2020, the first FIGHT KIDS CANCER call for projects led to the selection of six innovative research projects for a total of 3 080 000€, from which 800 000€ are financed by KickCancer (see the projects above). The second 2021 call, launched in 2020, was a great success in terms of the number of applications and led to the selection of 5 new research.

**Structural funding for the Belgian Society for Paediatric Haemato-Oncology**

The Belgian Society of Paediatric Haematology-Oncology (BSPHO) brings together doctors and healthcare professionals from the 8 recognised Belgian paediatric haemato-oncology centres.

The BSPHO coordinates scientific collaboration among professionals through the organisation of meetings, working groups and conferences. The BSPHO also coordinates and initiates the participation of the Belgian centres in international academic clinical trials.

Until 2020, the BSPHO’s activities relied mostly on the National Coordination Cell (1.7 FTEs), the salaries of which are funded through the Belgian Cancer Plan.

Together with the King Baudouin Foundation, KickCancer supported the BSPHO in its effort to identify ways to further develop the organisation, its processes and efficiency.

From that analysis, the BSPHO identified the need for a general manager to supervise its operations and coordinate its strategy – which would still be defined by its board of directors.

Pierre Mayeur took up the position of Managing Director of the BSPHO in June 2020 and with him, we are looking forward to further supporting the BSPHO to optimise its processes as well as the collaboration between the eight paediatric haemato-oncology units in Belgium to further improve the quality of care offered to children and young adults with cancer in Belgium.

KickCancer funds the position of Managing Directors as well as the necessary tools that allow an efficient collaboration within the BSPHO (Coordination Cell and all centres).

**European Institutions**

If 2018 and 2019 were slow years in Europe in terms of legislative initiatives, what can be said about 2020?

It was a feast of initiatives in the field of health and our heads were literally spinning! Which is great news for young patients with cancer.

Involvement within the European umbrella organisation for paediatric cancer patients

In this context, in 2020, KickCancer decided to step up its participation in the European paediatric cancer overarching organisation: Childhood Cancer International Europe (CCI-E). Delphine Heenen became a member of their Regional Committee in August 2020 and took the lead on the European Affairs pillar, next to her active participation in the pillars on innovation.

In order to foster more visibility on paediatric cancers, together with CCI-E, KickCancer contributed to creating a toolkit to help all CCI-E members to participate in the most important public consultation – the one on Europe’s Beating Cancer Plan. Paediatric Cancer organisations ended up constituting a significant share of the responses to the consultations, which eventually led to the creation of the flagship initiative on paediatric cancers.

Advocating changes for those regulations requires us to contact members of the European Parliament and the staff of the European Commission as well as to participate in the European legislative process, which includes contributing to public consultations. In 2020, we contributed to no less than 5 public consultations and encouraged the participation by as many other paediatric cancer organisations as we could.

We also prepared a position paper on all ongoing initiatives in Europe.

**Major initiatives for paediatric cancers**

These are the major legislative initiatives underway on which we have been most vocal.

One of Europe’s window initiatives for the current Commission is Europe’s Beating Cancer Plan. The Plan includes four main areas of work: Prevention, Early Detection, Treatment and Care and Follow-up of Survivors, most of which will impact research on cancer. It also includes ten flagship initiatives, including a specific one on paediatric cancers.

**Horizon Europe** is a major initiative which finances research in various areas but it always includes some specific areas of focus - among which the “Cancer Mission” that will invest 2 billion euros in research on cancer. It includes a specific initiative on paediatric cancers “Cancers in children, adolescents, young adults – cure more and cure better”.

The Pharmaceutical Strategy is also under revision. This has the potential to ensure accessibility of all standard-of-care drugs (availability in all EU Member States but also affordable prices) and to improve the competitiveness of European companies.

The Paediatric Medicines and Orphan Drugs Regulations were also both open for revision in 2020 – the procedure is ongoing in 2021. Amending these regulations could bring several benefits to paediatric cancer patients:

- It could become mandatory for pharma companies to invest in various areas but it always includes some specific areas of focus - among which the “Cancer Mission” that will invest 2 billion euros in research on cancer. It includes a specific initiative on paediatric cancers “Cancers in children, adolescents, young adults – cure more and cure better”.

**KickCancer’s second line of action to improve treatments available for children with cancer is to connect with all the players in the field (doctors, researchers, regulatory authorities, pharmaceutical industry and other philanthropic organisations active in the field of cancer). Understanding and listening to the players’ constraints is crucial to create a more favourable regulatory and environmental climate for a swifter access to innovation for children with cancer.**
1.3. Events

**ECLAIR DAY**

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

Saturday November 21st, 2020 was the first Eclair Day. Each participating (pastry) baker offered its signature eclair at a different price than the regular eclairs. This amount was entirely donated to the KickCancer Foundation to finance research on children’s cancer.

This new action could claim a quite prestigious godfather: Pierre Marcolini himself.

This first edition was a sweeping success and it was impossible to resist the temptation to organise a second edition. Mark your calendars: Saturday November 20th 2021 will mark the second Eclair Day!

**RUN TO KICK**

On September 27th, 2020, KickCancer organised the third edition of RUN TO KICK, a charity family race. In 2019, we had gathered 1350 runners that raised 625 000€ together. Last year, we all know that it was not possible to run together.

So what? Did you REALLY think we would skip the opportunity to kick cancer as it rightfully deserves? NO WAY! BAM!

We organised a connected race where our kickers safely ran in their own neighbourhood, and we gathered in front of a screen to share a beautiful moment together. Angèle’s closing concert ensured an enchanting experience for our runners – we also discovered some side benefits to a connected event: people can follow us from everywhere, even in the hospital! We shall keep the live broadcasting of our race in the coming years even if we strongly believe that being together is the strongest medicine of all to feel the solidarity among us.

This connected event rallied 750 runners and allowed us to raise 610 000€, quite a success in a pandemic world! But we do know you are the best supporters ever!

In 2021, we are excited to announce that RUN TO KICK will take place in real life! How kicking! Register now for September 26th, it will be a firework of fun, emotions and joy. And you will contribute to finance the best innovative research projects from across Europe.
A “fun & healthy” way to support a good cause.

“Service to others is the rent you pay for your room here on earth.”
— Mohammed Ali

Fight cancer while sporting with friends & family.

Great Chance for kids to contribute to something really worthwhile for other kids.
1.4. Raising awareness

Medias

KickCancer benefited from an increased media attention thanks — in part — to Angèle’s support to our cause. As a result, we benefited from a peak of articles in the written press and on the radio in September 2020 when she announced her participation in RUN TO KICK.

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

In 2020, we also developed a fruitful relationship with a PR agency, Talking Birds, who ensures our media presence while conveying the right messages about paediatric cancers.

Awareness campaign

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

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

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

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

4 4

TELEVISION APPEARANCES RADIO SHOWS

90

ARTICLES IN THE WRITTEN PRESS

I DARE YOU TO TELL PEOPLE YOU HAVE CANCER.

Children’s cancer. I donate.

kickcancer.org
2. Financial Report

2.1. Overall results

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

Sources of funds

<table>
<thead>
<tr>
<th>Source</th>
<th>Amount</th>
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</thead>
<tbody>
<tr>
<td>Registrations</td>
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<td>Sponsoring</td>
<td>161,372</td>
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<tr>
<td>Donations</td>
<td>1,198,503</td>
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<td><strong>TOTAL</strong></td>
<td><strong>1,367,436</strong></td>
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Usage of funds

<table>
<thead>
<tr>
<th>Usage</th>
<th>Amount</th>
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</thead>
<tbody>
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<td>Registration projects</td>
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<td>Advocacy</td>
<td>3,580</td>
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<td>Reserve for future</td>
<td>158,149</td>
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<td>Invested projects</td>
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<td>Awareness</td>
<td>229,144</td>
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<tr>
<td>Organisation of RUN TO KICK</td>
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<tr>
<td>Awareness (brochures, events...)</td>
<td>133,953</td>
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<tr>
<td>Administration</td>
<td>210,234</td>
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<tr>
<td>Investments</td>
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<td>Reserve for future admin costs</td>
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<td>Salaries</td>
<td>123,447</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>1,367,436</strong></td>
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</table>
2.2. Fondation KickCancer

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

Sources of funds

<table>
<thead>
<tr>
<th>Source</th>
<th>Amount</th>
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<tbody>
<tr>
<td>Registrations</td>
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TOTAL 606,976

Usage of funds

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<td>Awareness (brochures, events…)</td>
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<td>Salaries</td>
<td>123,447</td>
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</table>

TOTAL 606,976

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

3.1. The board

Founders & Family representatives

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

Professional directors

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

The permanent team consists of five people: Delphine and four other kickers with superpowers:

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
</table>
| 1 | Adeline Godefroid  
Kicker-in-Operations  
   |
| 2 | Nathalie De Clercq  
Kicker-in-Marketing  
   |
| 3 | Delphine Messiaen  
Kicker-in-Communication  
   |
| 4 | Alice Gerbaux  
Kicker-in-Advocacy  
   |

To make a donation

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

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

Contact us: info@kickcancer.org

www.kickcancer.org

Help us to kick and make a difference for kids with cancer by making a donation and amplifying our voice on social media.
CURE. DON'T CRY.