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

I am delighted to present our second annual report. I wish this report was a first step to a rising routine for KickCancer, but it will be somewhat peculiar: the covid-19 health crisis makes this year 2020 so much more uncertain for us all.

Yet, our determination does not falter: a pandemic, however serious, cannot put all other activities in the field of health to a halt. Children with cancer deserve the best treatments and when they fight against the disease, the clock is ticking: we have to keep acting today and with the same level of energy!
Over the course of its third year of existence, KickCancer has had the opportunity to sharpen what defines its identity and makes it unique: its presence both in Belgium and in Europe, its independence towards any kind of organisation (hospitals, pharma companies...) and its drive to collaborate with every single player: industry, governments, academia and other NGOs fighting against cancer.

In 2019, we were able to complete some of our first projects – which is a source of great pride for us because they will structurally impact the landscape of paediatric oncology in Belgium and in Europe.

We succeeded in putting together the website childrencancer.be thanks to an identification work of all organisations active in Belgium in the field of paediatric oncology, that we led together with the association Tuki. Thanks to this website, it will be easier for patients and parents to identify which organisations offer the support they are looking for in their region.

We kept developing our concept of joint race together with Imagine for Margo from France and the Fondatioun Kriibskrank Kanner from Luxembourg and gave it a common name: FIGHT KIDS CANCER. The funds raised during our three races will be jointly invested in European research projects selected by international independent experts. At this date, we have received 23 applications sent from throughout Europe and we shall announce the selected projects on June 11th, 2020.

In 2020, KickCancer is ambitioning to launch three major new projects.

We are putting in place a patients’ committee in order to institutionalise the presence of young patients with cancer and of their parents. Patients have indeed a unique experience to share that can feed the discussions: the experience of their disease and of remission. No serious research or healthcare policy can be elaborated without taking that experience into account or it would risk missing its objectives. In 2020, we want to offer a training to about 20 patients so that they can participate in ethical committees, assess research projects or offer peer-to-peer support to other patients... Next to those expert patients, we also want to gather a wider community of patients that will participate in surveys or focus group discussions. Those patients will enable us to demonstrate with politicians the reality of certain difficulties experienced by our constituents or will enable us to improve our own understanding of their needs and help them and their family better.

Furthermore, the European Union initiated in 2019 two major projects that will require a significant mobilisation on our part: the definition of a Cancer Mission in the framework of the financing scheme Horizon Europe and the drafting of a cancer plan “Europe’s Beating Cancer Plan”. Those two projects are very exciting but they might not benefit to paediatric cancers. Those latter cancers are indeed so specific that it would be easy to conceive a project entirely based on the needs of adult cancers and totally unfit for
younger patients. We are going to have to advocate with the European institutions in order to make sure that the specific needs of young patients with cancer be taken into account.

This leads us naturally to our third major project: when we talk about paediatric cancers to “people” around us, they are quite surprised… over the last three years, we have come to realise that a vast majority of people does not know anything about paediatric cancers. This is the reason why we want to launch a major awareness campaign about children’s, adolescents’ and young adults’ cancer.

Fortunately, to carry that work, our team grew over the last few months. Discover our new kickers in chapter 3!

We are eager to embrace 2020 to its fullest and more than ever, we shall need your support to make sure KickCancer’s activities keep on thriving!

Delphine Heenen
Kicker-in-Chief and Executive Director
Our mission

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

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**Every kid cancer is a rare disease**

There are about 18 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. Each of them requires a specific scientific attention.

35,000 new cases in Europe / year

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**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

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**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 in 2020. We must make sure that those long-term sequelae are either prevented or properly identified and treated.

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

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**Kids cancer cure rate stalled over the last fifteen years**

Interestingly, this is when most significant progresses occurred in adult oncology. Indeed, over the last 10 years, 200 new anti-cancer drugs were approved for adult malignancies. Over the same lapse of time, only 5 anti-cancer drugs were approved for paediatric malignancies. We must overturn these numbers!

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**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 be discovered in paediatric oncology and that more clinical trials open for the benefit of children with cancer.

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**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.
1. Activities report

KickCancer is pursuing to improve treatments for children with cancer by funding seven research projects.

**Two projects with ITCC: 300,000 euros over 1 year**

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 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. In some types of cancer, but not rhabdomyosarcoma, it has been shown to be clinically useful to assess abnormal DNA released from a cancer into the bloodstream. This technique is called "liquid biopsy" and its purpose is to collect cancer cells in the blood as opposed to a sample taken by surgery.

This study aims to validate the usefulness 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. In practice, if the correlation is confirmed, patients could be followed with simple blood tests instead of MRIs (which requires anaesthesia for younger patients). Doctors will also be able to reorient the patient more quickly towards a new therapeutic strategy when those patients do not respond to treatment or relapse.

The final report on this project is expected for the end of the first quarter of 2020.

**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 pontic gliomas (or DIPG) represents the most severe form, universally incurable with hardly any patients surviving more than 2 years after the diagnosis.

This project already allowed to identify two distinct sub-groups of DIPG within what we used to think constituted one single group, thanks to an analysis of their differences at an epigenetic level. Epigenetics study the expression or regulation of the genes: it focuses on the sequences of the gene and analyses which are activated, and which are not (this activation makes it possible to explain why cells with the same DNA fulfil different functions in our body).

These results will allow 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.

The final report on this project is expected for the end of the first quarter of 2020.
A clinical trial for refractory or relapsing solid tumours: 150,000 euros over 3 years

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

The clinical trial will take place in six French hospitals and in Belgium, in the university hospital of Ghent; 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. The first phase entails the recruitment of 12 patients in three treatment arms and will be completed around the end of second quarter 2020.

A data manager for a European organisation of doctors: 93,000 euros over 3 years

The data manager allows the EPSSG, the European association of paediatric oncologists specialised in soft tissue sarcoma, to analyse data from a completed clinical trial from new angles and to make the data interoperable with similar US databases. The goal is to validate a new international classification method with uniform risk groups in order to refine and improve patient treatments on the basis of their risk group.

The project delivered its first results: two subgroups of patients have changed risk category. Specifically, in the most recent 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.

A coordination unit for clinical trials in Belgium: 100 000 euros per year

Most clinical trials are coordinated at a European level in paediatric oncology; however, each participating country must have the clinical trial approved at its own national level and for so-called «academic» trials (which are not funded by a pharmaceutical company), seek its own funding.

The Belgian Society for Paediatric Haematology-Oncology (BSPHO) coordinates the set-up of those trials for Belgium among other general missions aimed to Belgian young patients with cancer.

Together with the King Baudouin Foundation, KickCancer supported the BSPHO in its effort to identify the levers for improvement of its work. We also financed the set-up of an informative website for the patients in three languages. The BSPHO decided to hire, thanks to KickCancer’s financial support, a general director that will help the doctors to coordinate their work and to focus on their main mission: care, and to free them from administrative burden of the coordination. This general director will start working in June 2020 and with him, we are looking forward to further support the BSPHO to optimise its processes.

Because our support aims at financing the position of a general director, KickCancer’s commitment is meant to last over time. The underlying vision, of course, is to support the collaboration between the several paediatric oncology units in Belgium in order to improve the quality of care offered to children and young adults with cancer in Belgium.
1.1. Research Projects

E-SMART: an innovative pan-European clinical trial

E-SMART is an ongoing clinical study with an adaptive design for early-phase study of novel drugs in children:

- Adaptive design means that the study allows for the testing of several drugs simultaneously and that it can be amended to include new drugs without going through the administrative burden of opening a new trial.

- The tested novel drugs are drugs which are currently in development for the adults and which show promises for paediatric cancer.

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

The study first opened in France in 2016 and will be expanded to 5 new countries: the Netherlands, the UK, Spain and soon in Italy and Denmark. It is coordinated through the ITCC network (Innovative Therapies for Children with Cancer). Our financial support will allow the opening of 3 new treatment arms.

KickCancer will finance the equivalent of one year of costs of this study or 413,571€. Simultaneously, Imagine for Margo (France) and Fondatioin Kriibskrank Kanner (Luxembourg) will also finance the study.

This project has been selected for financing in the framework of competitive processes by the INCA (Institut National du Cancer, France) and CRUK (Cancer Research UK), two major well-known organisations in the field of cancer research in Europe.
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 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.

In this respect, 2019 was a quieter year: Europe has been through a transition period as a result of the elections, while Belgium… does not have a federal government yet.

European Institutions

Before elections, European institutions tend to go on hibernation mode in order to avoid that major decisions be approved while a new commission is underway.

We prepared the elections in collaboration with several other European organisations and the support of the European Society of Paediatric Haematology-Oncology and issued a position paper advocating several legislative amendments in order to accelerate access to innovative treatments for children, adolescents and young adults with cancer (“young patients”).

We sent our position paper to all the new members of the European Parliament who are members of the health or research commissions, which represents about 150 people in total. It came along with a congratulation letter as well as general documents explaining what paediatric cancers’ specificities: you might say it was a sort of welcome pack!

Simultaneously, the European Commission prepared the work of the future commissioners by organising in June 2019 an interactive day about paediatric medicines and the regulation on orphan diseases. It gave us the opportunity to defend the need to stimulate not only the transposition to paediatrics of drugs developed for adults but also the development of purely paediatric drugs, which would be conceived on the basis of our specific knowledge about paediatric cancers.

To that end, we must support research in paediatric oncology and create a favourable legislative framework for developments in ultra-rare diseases. There is also a category of potentially attractive drugs for children, which are unfortunately out of reach today: cancer drugs initially conceived for adults, which failed in that population and about which there are serious assumptions that they might benefit children and young patients with cancer. Today, there is no mechanism enabling us to mandate a continued development of those drugs by the patent holder or its transfer to an entity that would be interested in taking such development over.

These are some of our goals for 2020.

1.3. childrencancer.be

When we founded KickCancer, we had a really hard time identifying what already existed in the field of paediatric cancers in Belgium. It was paramount for us to avoid any sort of duplication of existing efforts: one of our signature trademarks is that we want to collaborate and join forces. As a result, one of the first things that we did was asking all the paediatric oncology units in Belgium to give us a list of the associations that they know and work with on a regular basis.

We contacted the organisation Tuki from Limburg and offered to call all those organisations in order to find out whether they would be willing to be listed on one single website (first step) or to participate to a joint effort to create an overarching organisation (second step).

Over the course of a dozen meetings, during which all those organisations were meeting each other for the first time, we discussed, drafted and signed a charter containing common values. Signing the charter is indeed a pre-requisite to be listed on the website childrencancer.be.

All organisations listed on the website undertake to protect the dignity of the patients whom they help, to refrain from interfering in the relationship of trust between a caregiver and its patient or its family. The fact that any organisation is listed on the website childrencancer.be is accordingly a quality stamp for future donors or volunteers. For the associations themselves, it is also the possibility to strengthen each other by sharing their best practices and by referring their patients to each other in a more fluid fashion if those patients can benefit from it.

Now that the website childrencancer.be is online, patients will gain time when they need to identify the organisations that offer the support that they need in any region thanks to research filters.

KickCancer, Tuki and Kinderkankerfonds are the managing organisations of the website. Our goal in the longer run is to create an overarching organisation under which all Belgian associations could speak with one voice in order to represent young patients with cancer.
1.4. EVENTS

RUN TO KICK

On September 29th, 2019 KickCancer organised the second edition of RUN TO KICK, a charity family race. We managed to gather 1350 runners that raised together 625 000 euros. The weather was clearly disappointing, but the participants made the best of the situation and came massively to defy the rain and violent winds! The emotion was at its peak on stage when the prizes were handed over by Angèle. For the people attending the event, the warmth coming out of RUN TO KICK is an unforgettable and peculiar experience. We hope they will find it as addictive as we do.

It is very likely that 2020 will be a different edition but the show will go on and it will take place. We must continue to support research and keep fundraising. Besides, families who have been through the experience of cancer of one of their children need to feel the warmth, solidarity and support from their friends or colleagues! We are accordingly going to opt for a radically new (and exceptional) type of event: together but apart, connected thanks to technology.

Register for September 27th, 2020, raise funds and let us surprise with our imagination without limits. You might not believe but you will experience a sweeping wave of solidarity, emotions and togetherness that are the signature traits of RUN TO KICK.

Winners’ Cup

In 2017, Inter Milan organised for the first time a soccer tournament: teams of adolescents and young adults who survived cancer would compete against each other.

The first two editions of this tournament were disputed by Italian teams only. The third one opened its doors to Europe with six teams (Belgium, France, Germany, Greece, Spain and The Netherlands) and 10 Italian ones.

Under KickCancer’s supervision, twelve young adults defended the colours of Belgium. Before the tournament, they benefited from a few weekly practice sessions and received a sport gear from our generous sponsor decathlon.be.

We could unveil the results of the tournament, but that would be missing the point.

The tournament was organised with the aim to shed a light on the specific needs of adolescents and young adults with cancer (15 to 24 or 26 years). The care facilities are less adapted to their psychosocial needs because they are stuck between two age groups (infancy and adults).

As a result, some adolescents and young adults have a lower cure rate than children with the same malignancy.

To cure more cancers and to improve the quality of life of survivors, we must not only ensure that new treatments are developed: we must also create infrastructures allowing patients of all ages to be treated according to their needs, in a bed of their size and attended by a doctor specialised in their pathology. These infrastructures must also allow these patients to meet their peers with whom they can share their experience.
RUN TO KICK is een tof concept, vrienden deden mee dus maakte het ook aangenamer om zelf deel te nemen.

Life is stronger, nothing is ever achieved alone, we are all together in this fight.

La magie de RUN TO KICK, c’est le partage avec les autres, la motivation émanant de l’événement, la passion des organisateurs et bénévoles, le sentiment de lutter tous ensemble contre la maladie.

Ce qui me motive dans la course: 100% des dons sont reversés à la recherche et faire quelque chose en plus que « simplement » récolter des fonds.

It is important to raise awareness to the lack of research in this particular and important field. Also, it is important to create solidarity in the local communities of families facing such a huge challenge to defeat the cancer of a child. It is important that brothers and sisters who lost their brothers and sisters can speak about it and have their surroundings accept/face this fact too and help them live with it.

Wat ik het liefst had met RUN TO KICK: heel het bedrijf samen een doel bereiken, algemeen gevoel van impact en de aanwezigheid van Angèle!

It is important that brothers and sisters who lost their brothers and sisters can speak about it and have their surroundings accept/face this fact too and help them live with it.

La maladie nous ayant touché de près, il nous semblait normal de “travailler” à récolter des fonds pouvant faire avancer la recherche.

Ik vond het hele concept en de sfeer ter plaatse geweldig, en leuk te zien dat mensen ondanks het slechte weer toch met velen zijn komen opdagen.

It is important that brothers and sisters who lost their brothers and sisters can speak about it and have their surroundings accept/face this fact too and help them live with it.

La magie de RUN TO KICK, c’est le partage avec les autres, la motivation émanant de l’événement, la passion des organisateurs et bénévoles, le sentiment de lutter tous ensemble contre la maladie.
1.5. Raising awareness

**Medias**

KickCancer benefited from an increased media attention thanks -in part- to Angèle’s support to our cause. As a result, we benefitted from a peak of articles in the written press and on the radio in May 2019 when she announced her support to RUN TO KICK and around the date of the race itself, at the end of September.

**Support from other organisations**

In 2019, KickCancer was selected by the Fighters Against Cancer as “Fight of the Year” again next to the Limburg ASBL Tuki. The Fighters Against Cancers are carried by our friend Bert Van Mechelen. They organised an incredible family day, as well as several other activities, sold loads of t-shirts. In the end, they handed us a very generous check of 50 333 €.

2019 also started full speed thanks to Stéphane Henrard, professional automobile runner, and Gatien du Bois, a former cancer patient. They followed the tracks of the Dakar by carrying KickCancer’s colours across the desert and they managed to secure an impressive 14th position! This exploit was also the occasion for them to talk about us and our fight for better cures with the media and to raise funds. A documentary about their adventure will come out soon..

In September, Noémie Tellier, a committed hockey player, organised SHOOT TO KICK for us, a shootout contest—for the non-initiated, shoot-outs resemble penalty shootouts in football. 90 young people competed against Vincent Vanash, the goalkeeper of the Red Lions, and Elodie Picard, the goalkeeper of the women’s national team. Vincent and Elodie gave their all for our young players — stopping most balls, but not all. The event allowed to fundraise more than 11 000 €.

In October, it was Maïté Czupper’s turn, manager of MC Boxing, to organise a boxing gala for us: PUNCH FOR LIFE. The evening included six amateur boxing matches, with brave boxers who committed to raise funds for research. More often than not, the boxers were stepping into the ring for the first time of their life for a competition in front of a real audience. In the end, 50 000 euros were raised for the benefit of research against childhood cancer.

Thank you, to each one of you: Bert, Stéphanie, Gatien, Noémie and Maïté for your commitment on our side and the precious time you devoted for the organisation of those activities to our benefit!
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

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Usage of funds

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2.2. Fondation KickCancer

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

### Sources of funds

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### Usage of funds

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</tr>
<tr>
<td><strong>TOTAL LIABILITIES</strong></td>
<td><strong>493 889</strong></td>
<td><strong>207 767</strong></td>
</tr>
</tbody>
</table>
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:

1. Adeline Godefroid
   Kicker-in-Operations
2. Josefien Vermeersch
   Kicker-in-Advocacy
3. Sara Stals
   Kicker-in-Communication
4. Nathalie De Clercq
   Kicker-in-Marketing

3.3. KickCancer’s extended family

KickCancer also exists thanks to motivated free-lancers, directors who give their time outside of the board meetings... on this picture, you will see them all gathered for our Christmas lunch 2019:

Simon Demeuter – Cartoonist
Céline Ghins – Director
Nathalie De Clercq – Kicker-in-Marketing
Gilles Dal – Director and founder
Grégoire Vanderheyden – Graphic designer
Marc Dal – Director and founder
Julie Wadin – Web developer (Shine)
Hélène d’Udekem d’Acoz – Director
Jean-Charles van den Branden – Director and founder
Delphine Heenen – Director and founder
Adeline Godefroid – Kicker-in-Operations
Thomas Carton – Web developer (Shine)
Thomas Perissino – Web developer (Shine)
Lukas Van den Cruys (replaced by Sara)
Kicker-in-Communication
Josefien Vermeersch – Kicker-in-Advocacy
Alexandre Stroobants – Web developer (Shine)

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

To make a donation
Fondation King Baudouin – KiCa Fund
BE10 0000 0000 0404
Communication: 016/1860/00070

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, administration and soft power.

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