

**kick cancer**

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

Annual Report  
2017-2018

## A few key metrics

**More than 1.6 millions euros raised over two years**

**5 research projects financed for 743.000 euros and a 6<sup>th</sup> one currently being finalised for 100.000 euros**

**680 registered runners at RUN TO KICK, who requested the generosity of nearly 4.000 donators**

**12 articles in the print media, 4 radio broadcasts and 3 television appearances**

**7 people who contribute as employees, freelances or volunteers to the success of KickCancer (and soon some new recruits)...**

**Participation in 12 international conferences on research or improvement of access to treatments**

### © Photos

Lydie Nesvadba  
cover, p11, p16, p21, p23, p24

John Stapels  
p13 (top), p14-15

Laurent Van Steensel  
p13 (bottom)

**Dear KickCancer supporter,**

**We are delighted to present you our first annual report. This first report is not only special because it is our first, it is also special because it exceptionally covers almost two years of activities.**

Over the course of these two years, we have worked very hard on laying the first ground of our identity with a kicking website, brochures or a newsletter but mostly with **the fundamental work of defining our mission and what we stand for.** To get there, we ran from conference to congress in order to meet the international, European and Belgian communities of paediatric oncology and engage in our first exchanges in the field with key opinion leaders, ground-breaking researchers, high-ranking politicians and most daring charities. (...)

We have created a brand name for our foundation with some success in the Belgian media and a **serious reputation** in the world of paediatric oncology. KickCancer participated in many events as guest speaker and we collaborate very closely with renown organisations from other European countries.

KickCancer wants to contribute to **improving the structures of paediatric oncology by reinforcing international collaboration on research projects and strengthening the Belgian network of clinical trials**. These goals have shaped our choice of projects — such as the structural financing of a Belgian coordination cell for clinical trials.

As we also want to foster a **European ambition for research** in paediatric oncology, we have to make sure that the most promising projects, wherever they originate from, are selected and financed. This implies encouraging collaboration among the biggest academic laboratories or unearthing the most creative, innovative projects from smaller research teams... This is why we have saved some of the funds that we have raised in the last few months in order to be able to set up an open **European call for research projects**.

For such a tender to be successful, we have to mobilise significant funds in order to make sure

that the best (academic) research teams are incentivised to participate. This call for project will be launched in the course of 2019 and we hope to set it up with other European charities in order to reach significant amounts that will raise the ambition of European researchers to a new exciting level in the field of paediatric oncology.

In 2019, we also want to **increase our political presence in Europe and Belgium** and for that, we are looking for a professional lobbyist to join our team. This will entail a serious investment for a young foundation like ours, as talent comes at a cost, but we believe that children deserve to be defended by the best possible advocate.

These are our two biggest projects for 2019. We hope you like them and please, as we very much enjoyed your company, bear with us for this exciting, kicking new year!

**Delphine Heenen**

Kicker-in-Chief and Managing Director

# 1. Mission statement

**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!**

## **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. Each of them requires a specific scientific attention.

w  
**35.000 new cases in Europe / year**

## **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**

## **2/3 survivors suffer from longterm effects.**

Nowadays, anti-cancer treatments are heavy and leave survivors with severe long-term sequelae. Survivors will represent about half a million people in Europe by 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

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

Interestingly, this is when most significant progresses occurred in adult oncology. Indeed, from 2011 to 2015, 70 new anti-cancer drugs were approved for adult malignancies. Over the same lapse of time, only 2 anti-cancer drugs were approved for paediatric malignancies. We must overturn these numbers!

# 2. Activities report

## 2.1. Research projects

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

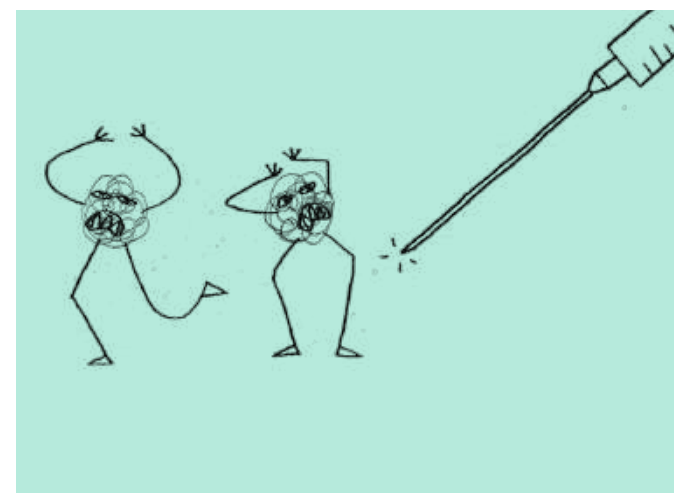
### Two projects with ITCC: 300.000 euros over 1 year

These two projects were selected in collaboration with the ITCC through a peer-reviewed projects tender.

#### 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.

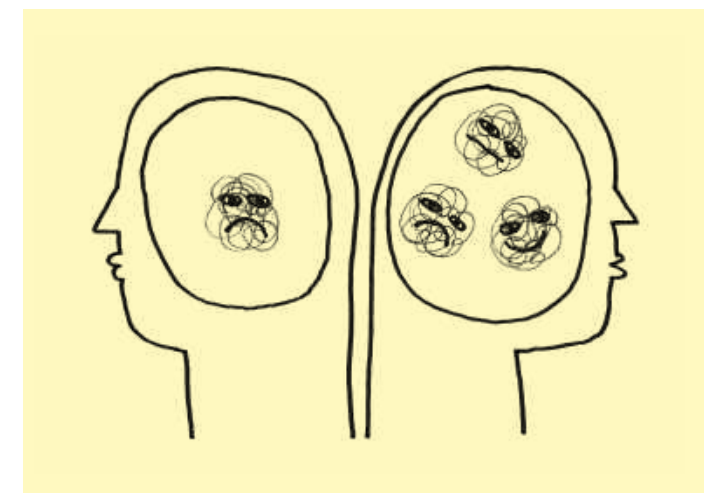
This study aims to validate the usefulness of the concept of correlation between the amount of rhabdomyosarcoma specific DNA found in the blood and the quality of the response of said patients to their treatment. In practice, if the correlation is confirmed, patients could be followed with simple blood 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.



#### 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 will characterise these two sub-groups of DIPG by scrutinising their differences at the 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 provided 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 they present the same genetic mutation.





## 2.1. Research projects

### Improving our understanding of the resistance mechanisms of high risks cancers: 200.000 euros over 4 years

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 (such as clinical trials), the results of this analysis will enable doctors to swiftly redirect patients towards the best therapeutic strategies.

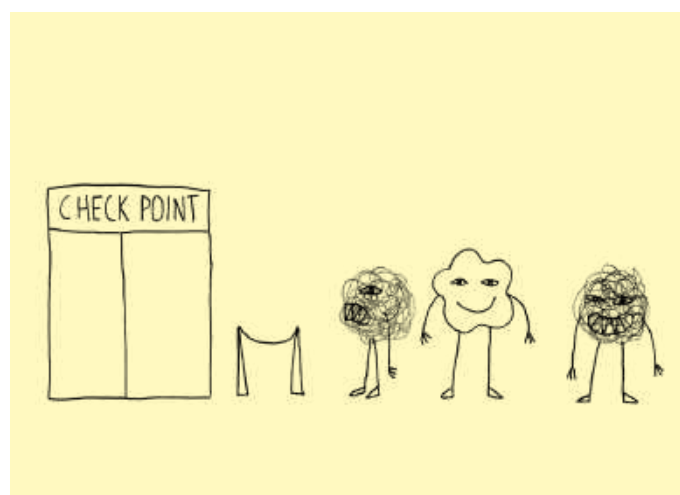
The recruitment of the first patients started in April 2018 and to this day, 31 patients were admitted into this trial.



### 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 checkpoint 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 will be open to patients with a solid tumour who do not respond to standard treatments or who are in relapse.

The project has been approved by the French ethics committee and has just started recruiting patients in the French centres. The trial in Belgium will open in the course of 2019.



### A data manager for a European organization 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 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.



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

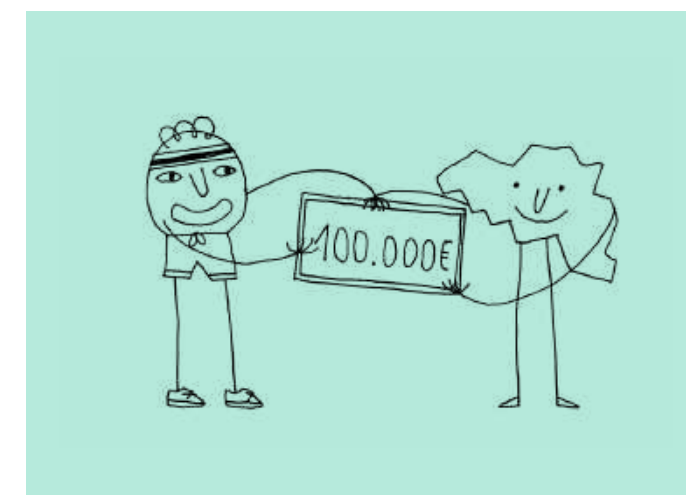
Most clinical trials are coordinated at a European level in paediatric oncology; however, each participating country must have the clinical trial approved at its own national level and for so-called “academic” trials (which are not funded by a pharmaceutical company), seek its own funding.

The Belgian Paediatric Oncology Association (BSPHO) currently does not have enough internal resources to sustainably support its efforts to participate in all European clinical trials. KickCancer is committed to allocating the first € 100.000 raised each year during the RUN TO KICK race to finance the first stones of this coordination cell.

The aim of this cell is to enable the Belgian centres to coordinate their research activities in order to make them more effective and improve the care provided to Belgian patients.

In conjunction with the King Baudouin Foundation, KickCancer will provide BSPHO with necessary resources to enable physicians to prepare their clinical trial files without encroaching on their clinical or research time.

Long-term development: In the longer run, KickCancer wants to convince other Belgian institutions to finance this coordination cell. The expansion will provide Belgian paediatric oncology centres with a structural and coordinated support for setting up and funding their clinical trials. The underlying vision, naturally, is to improve the therapeutic offer in Belgium for children with cancer.





## 2.2. Advocacy

KickCancer advocacy work also includes improving treatments available to children with cancer by connecting all the players in the field (doctors, researchers, regulatory authorities, pharmaceutical industry). 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' goal is to make the system more efficient.

### European Institutions

At the European level, KickCancer within Unite2Cure, actively contributed to the audit process of the European Regulation on Paediatric Medicines (consortium of patient associations from several European countries). The European Commission analysed and recognised the specific problems encountered in paediatric oncology. This result is considered as a huge success by the "specialists" of the sector.

In the wake of this audit report, the European Commission has issued a roadmap with a view to improve the implementation of the Regulation on paediatric medicines as well as to audit a similar regulation, the Orphan Drugs Regulation, in order to understand why there are so few investments in some fields of paediatrics, including oncology. KickCancer and Unite2Cure participate in this new audit. Thanks to our active contribution to those debates, KickCancer has built a strong credibility as a patient association with the European institutions and pharmaceutical companies. These discussions also allow us to promote cultural changes in the industry's practices – faster and easier to implement than regulatory changes.



### Belgian federal government

Not only does KickCancer have a significant presence on the European scene but is working on several projects in Belgium as well to make life easier for clinical oncologists and to raise awareness on paediatric cancers.

The first project is linked to "off-label" drugs. When a drug is authorised, this authorisation relates to a specific use: a given disease, a specific formulation (pill, syrup, etc.) and a determined dosage ("on-label"). When a medicine is used outside this specific formulation (for example: according to different dosage or for another disease), the medicine is then used "off-label". In paediatric oncology, many drugs given to children are prescribed off-label. Their use has been tested through valid clinical trials, and the safety and effectivity of these drugs are demonstrated. Nevertheless, the company that produces those medicines did not ask for an official authorisation for this new indication.

These medicines used off-label however are included in international protocols and are regarded as the "standard of care": the best care to date for a given type of cancer.

A medicine prescribed off-label is not necessarily reimbursed in Belgium. As a result, several drugs listed in paediatric oncology protocols are not reimbursed by the RIZIF/INAMI.

This leads to administrative work overload for doctors, social services and the pharmacy of Belgian hospitals, which has no added value for the quality of care for the patients while philanthropic organisations end up dedicating funds to medicine bills to the detriment of other activities.

Unlike Belgium, many European countries reimburse off-label drugs in paediatric oncology.

KickCancer co-wrote an article with the Association of Belgian Paediatric Oncologists, asking for a structural change of regulation in Belgium to allow for the reimbursements of off-label drugs when they are included in an international protocol. First meetings with the cabinet of the Minister of Health took place just before the fall of the government... this project will need to be re-initiated after the federal elections.





## 2.3. Attending & speaking at conferences

Financing research requires a serious commitment to understanding how research works and the creation of a real network within the scientific community.

For that reason, KickCancer attended 12 conferences in the course of 2017 and 2018. Some of these conferences are international (such those organised by SIOP or the “Société Internationale d’Oncologie Pédiatrique”), European (such as the Accelerate symposium or the EPSSG meetings) or Belgian (the annual BSPHO conference, organised by the Belgian Society for Paediatric Haemato-Oncology).

KickCancer also presented its advocacy work during numerous conferences. At the meter, in 2017-2018, we have made eight presentations during international, European or Belgian conferences. The topics vary from the need to have active patient advocates involved in the assessment of regulations, a critical assessment of the Paediatric Medicines Regulation to the need to create new commercial models to develop specifically paediatric oncology drugs.



## 2.4. Events

### RUN TO KICK

On September 30th, 2018, KickCancer organized the first edition of RUN TO KICK, a family charity race. 680 runners were gathered and collected, all together, nearly 330 000 euros. Participants ran with a smile on their faces and their joy was as palpable as their emotion. Feeling the presence and commitment of their friends, family and sometimes even colleagues was an unforgettable experience for families who had a child with cancer. From now on the foundation will organise RUN TO KICK every year as it was such a success.



680

RUNNERS

4000

DONATIONS

330k

EUROS  
RAISED

15

SPONSORS

60

VOLUNTEER  
WORKERS

### Tout va très bien

In January 2018, Gilles Dal’s play about paediatric cancer was on the bill for a whole month at the Théâtre de la Toison d’Or. It was the occasion to achieve the impossible: make an audience laugh about paediatric cancers.

The play was also the opportunity to celebrate the almost first year of activities for KickCancer and to have some press articles about our fight.

As a token of thankfulness, we invited many sibling organisations at the avant-premiere (Foundation against Cancer, King Baudouin Foundation and the Anticancerfund), caregivers, our early-bird supporters us and of course, friends and families.







“RUN TO KICK was geweldig om samen met een team collega's deel te nemen aan een project met een nobel doel. De ideale manier om je collega's te leren kennen buiten het gebruikelijke kader en met voldoende tijd voor elkaar.”

« J'ai voulu participer à RUN TO KICK car c'est une course familiale, parfaite et abordable pour les plus jeunes, les plus vieux ainsi que ceux qui ne courent pas. Nous pouvions ainsi la faire tous ensemble. »

« J'ai couru pour KickCancer parce que j'ai battu cette maladie et que je voulais donner quelque chose en retour. »

“I just loved running with my colleagues in the woods!”

« Nous avons participé à la course parce que nous avions envie d'impliquer nos enfants dans cette action et de les sensibiliser eux aussi. »

« J'ai été transcendée par la chaleur humaine et intergénérationnelle ainsi la forte présence des enfants... plein d'amour au sein de cette foule qui m'a semblé être juste une grande famille avec un même cœur pour RUN TO KICK. »

“RUN TO KICK gave us an enormous sense of gratification for helping the cause, and that's what we loved about it.”





## 2.5. Raising awareness

### Medias

In 2017-2018 (and really mostly since September 2017), KickCancer benefited from a very good media coverage, well balanced over the Northern and the Southern part of the country.

3

TELEVISION  
APPEARANCES

4

RADIO  
BROADCASTS

2

SUPPORT  
FROM OTHER  
ORGANISATIONS

12

WRITTEN  
PRESS ARTICLES

### Support from other organisations

In 2019, KickCancer was selected as “Fight of the year” by the **Fighters Against Cancer**. They organized an amazing family day to our benefit as well as many activities... in the end, they gave us 60,166 €. Thank you!

**Shoot for Good**, which aims at supporting and promoting amateur photography, also organised an event and exhibition to the benefit of KickCancer.

These activities enable KickCancer to increase its visibility thanks to the exposure to the network of new people, which is also very beneficial in the long term.



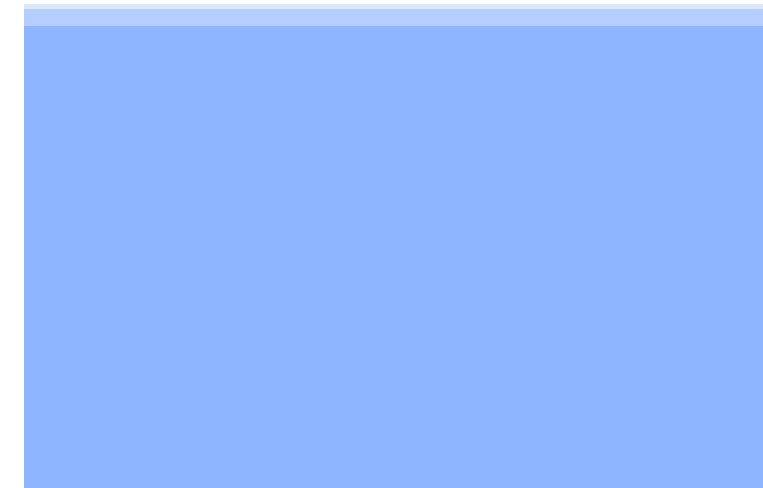
# 3. Financial Report

## 3.1. Overall results

As you know, KickCancer works closely with the KiCa 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 KiCa Fund.

### Sources of funds

TOTAL **1 593 115**



Registrations	16 079
Sponsoring	58 000
Donations	1 519 037

### Usage of funds

TOTAL **1 593 115**



87%

4% 9%

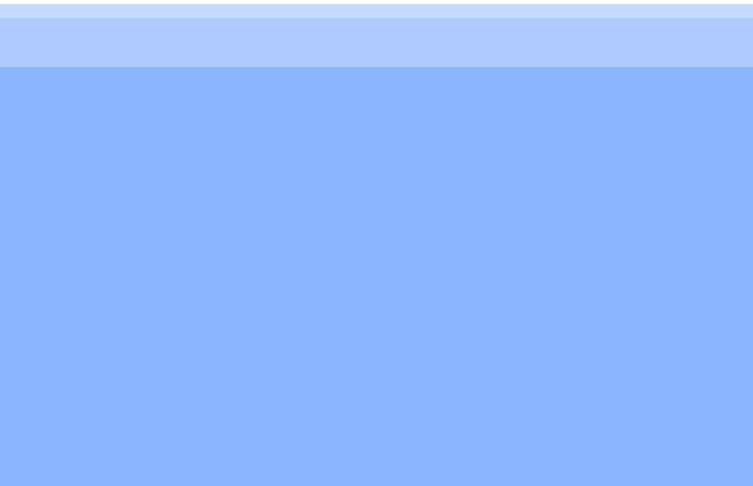
<b>PROJECTS</b>	<b>1 369 016</b>
Advocacy	11 972
Reserve for future projects	514 044
Invested projects	843 000
<b>AWARENESS</b>	<b>74 127</b>
Awareness (events, brochures...)	6 003
Organisation of RUN TO KICK	68 124
<b>ADMINISTRATION</b>	<b>149 972</b>
Reserve for future admin costs	5 647
Investments	8 984
Salaries	22 356
Administrative costs	112 985



## 3.2. KickCancer Foundation

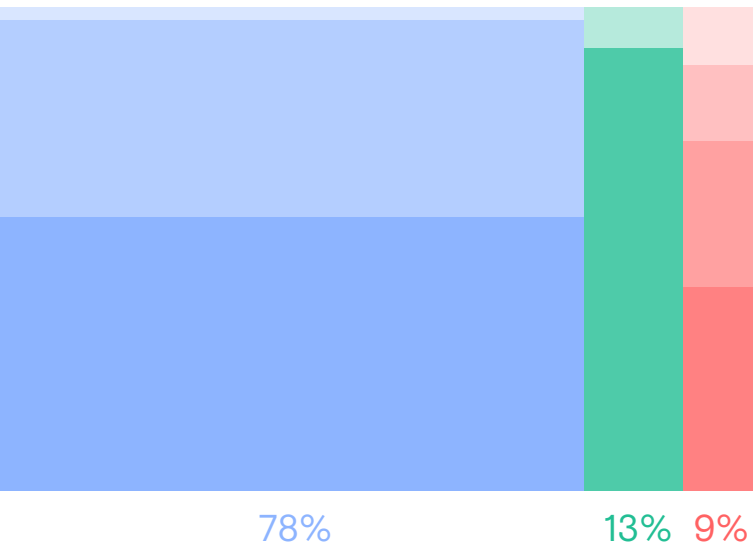
In this section, you will find the results generated by the KickCancer foundation alone.

### Sources of funds



Registrations	16 100
Sponsoring	58 000
Donations	494 300

### Usage of funds



PROJECTS	441 200
Advocacy	12 000
Reserve for future projects	179 200
Invested projects	250 000
AWARENESS	74 100
Awareness (events, brochures...)	6 000
Organisation of RUN TO KICK	68 100
ADMINISTRATION	53 100
Reserve for future admin costs	5 600
Investments	9 000
Administrative costs	16 100
Salaries	22 400

### Assets

FIXED ASSETS	25 040
Establishment costs	2 045
Intangible assets	22 240
Tangible assets	2 801
CURRENT ASSETS	182 727
Available Assets	182 322
Regularisation accounts	405
TOTAL ASSETS	207 767

### Liabilities

SOCIAL FUND	184 819
Establishment costs	2 236
Intangible assets	3 412
Tangible assets	179 172
DEBTS	22 948
Available Assets	17 430
Tax, social and salary debts	5 518
TOTAL LIABILITIES	207 767



# 4. KickCancer Team

## 4.1. 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

### Professional directors

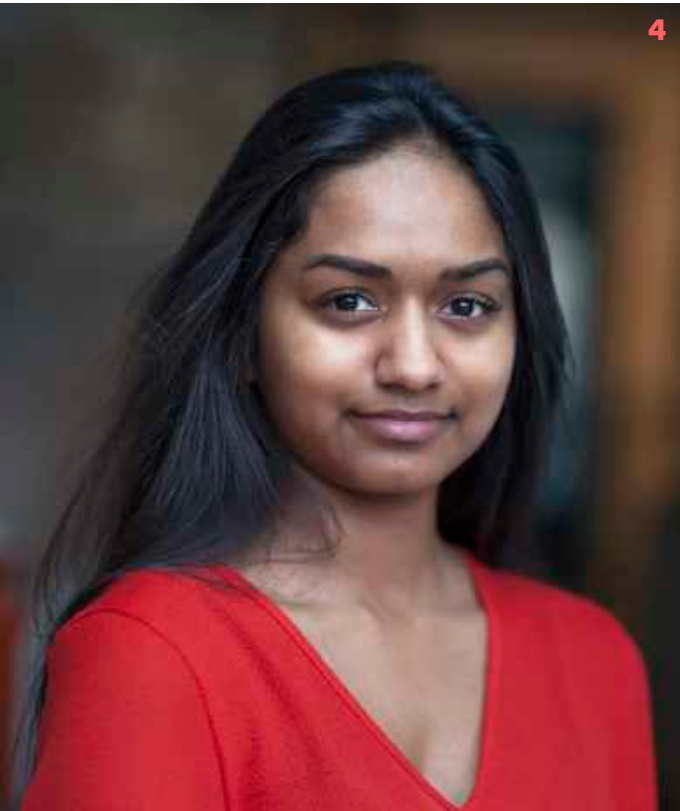
- 6** Deborah Janssens
- 7** Christophe De Vusser
- 8** Frédéric Rouvez
- 9** Jo Van Biesbroeck





## 4.2. Permanent team

The permanent team of KickCancer consists of out of 4 persons: **1 Delphine Heenen** and **2 Céline Ghins** as well as two other kicking team members:



**3 Adeline Godefroid**, Kicker in Operations, and **4 Melissa Thomas**, Junior Kicker.



**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: 016/1960/00070

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 90% of your donations will directly fund research or will go to our activities to defend children with cancer, less than 10% will be used for our communication, fundraising, administration and soft power.

Contact us: [info@kickcancer.org](mailto:info@kickcancer.org)  
[www.kickcancer.org](http://www.kickcancer.org)



**CURE.  
DON'T  
CRY.**

**kickcancer**

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**Contact**

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