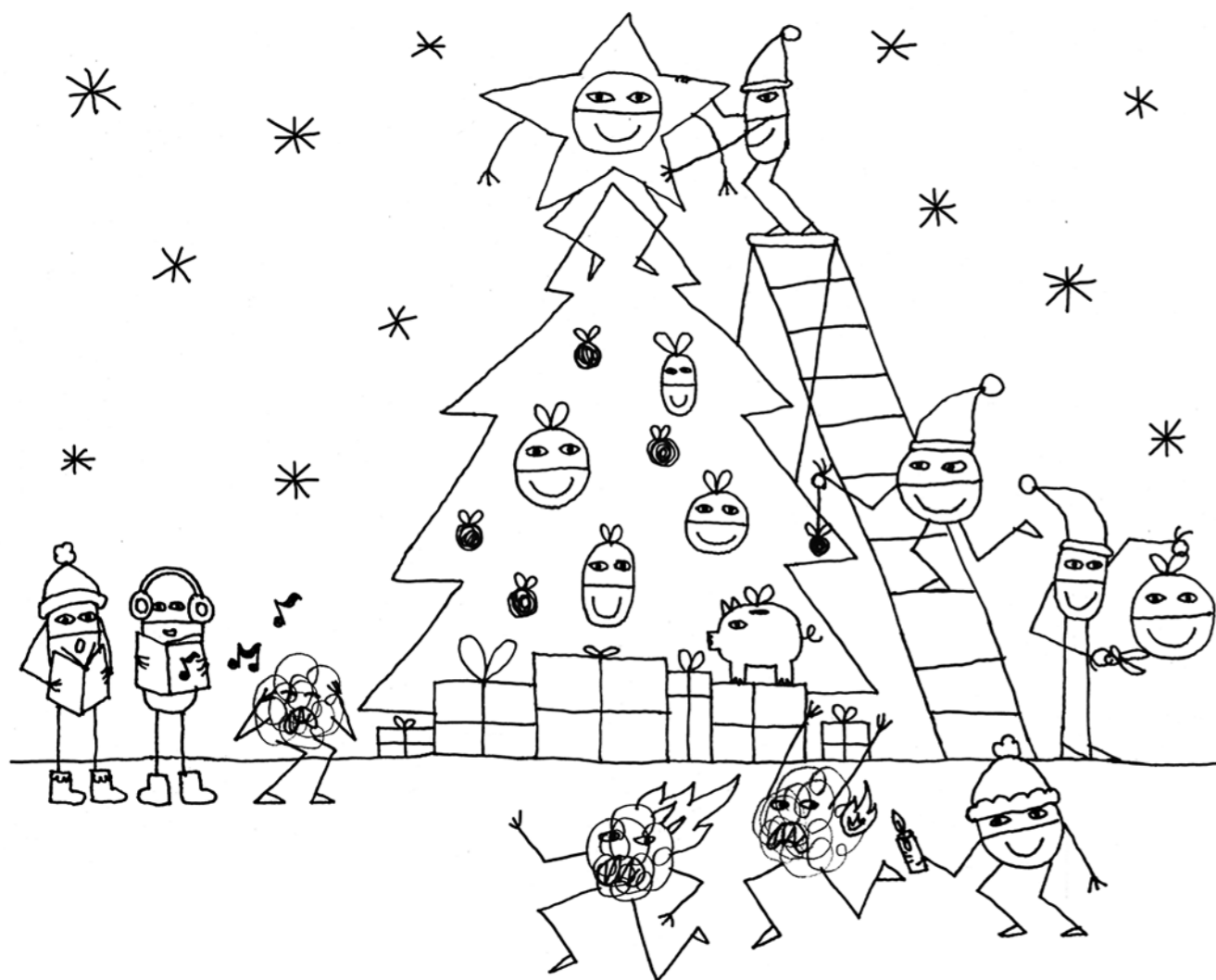


KickCancer

Winter News



Hello!

We closed the year 2019 with rocketing ambitions for 2020. But like many of our peers, we reviewed this ambition downwards in order to stay on track despite the challenges. But you were compelled by our projects and you bore with us beyond our wildest expectations: together, we were able to continue the promotion of better treatments for children with cancer. We are almost four years old now and ready to keep kicking for the long run! We are proud, almost emotional but definitely super excited to present to you this end-of-year newsletter. Let's move on swiftly to 2021 but before that, we wish you a lot of solidarity and warmth for the holidays' season.

The KickCancer Team

KickCancer 2020 in numbers

1 100 000 € raised over the year

12 000 éclairs eaten up for a good cause

750 RUN TO KICK runners

50 bakers united during the Éclair Day

7 new research projects selected in 2020

2 ambassadors who spread the word about us: Angèle and Gui Home

1 new juicy collaboration with think tomato

...

And yet 2/3 young survivors still suffering from long-term side effects.

kickcancer.org

Make a donation before the end of 2020: "If you adopt a Christmas donation attitude, You will enjoy eternal gratitude".

Wire transfer

KickCancer Fund – King Baudouin Foundation
BE10 0000 0000 0404
Communication: 016/1960/00070

Online – Kickcancer.org

In 2020 you will benefit from **exceptional tax savings of 60 % if you donate 40 € or more to KickCancer.**

More than 85% of your donations directly finance research or our advocacy work for children with cancer, less than 15% are used to make our awareness actions, fundraising activities and administration costs possible.



Patients Long-Term Follow-Up: a very first support to a Belgian initiative... with European ramifications

KickCancer's signature strategy is that we finance pan-European research projects. The long-term follow-up project is peculiar because it entirely Belgian and it will not only improve the quality of care for young patients but it will also enable our national oncology units to contribute more actively to the European research effort.

Today, in Belgium, 87% children with cancer are alive five years after their initial diagnosis. However, the treatments leading to their remission are exposing them to increased co-morbidities risk and premature mortality (up to 90% patients).

Many young survivors do not even realise the situation they are in, do not know which treatments they have been administered and in Belgium, there is no organised specific long-term follow-up plan that is adapted to their medical history. That type of medical consultation, which oftentimes needs to be much longer than a "standard" 20-minutes consultation, is not specifically reimbursed.



4 867 new cases concerning patients from 0 to 19 years of age have been recorded in the Cancer Register between 2004 and 2016. For these patients, the current data recorded are clearly insufficient (diagnosis date, type of paediatric cancer, information on 5-years survival and in some cases, relapses).

The Long-Term Follow-Up project will allow to complete the data and gather them into one single national standardised database with clinical information available for these patients: type of treatment received, relapse, secondary cancers, acute toxicity. Those data will be added to those of patients who have been diagnosed since 2017.

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
- 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 those of patients from other European countries;
- To provide each patient with a summary of the treatments they received and a tailor-made follow-up plan; as a result, those patients will be able to take care of their own health and not just suffer from those long-term side effects by, where possible, preventing or reducing them;
- Advocate with the Minister of Health the set-up of a specific financing for the "long-term follow-up" consultations.



Maëlle Deville, one of the project coordinators, paediatrician oncologist at the Cliniques Universitaires Saint-Luc

"Some patients who were treated long ago and who end up in my consultation are shocked and yet relieved **when they understand that all the seemingly unrelated health problems they are suffering from are all connected to one single event: the anti-cancer treatment they have been through** during their childhood. Setting up and standardising the long-term follow-up will allow to prevent and improve the treatment of many pathologies caused by the prior treatments. All in all, those patients will be healthier and it will benefit the entire society."



Hélène's testimonial, Alistair's mother

There is clearly a before and an after...

Four years ago, our two and a half years old son was diagnosed with a cavum rhabdomyosarcoma (we were complete strangers to those words until then).

Our world collapsed while we were still immersed in the joy of the birth of our third child a couple of months earlier.

There is one thing we did not know back then: our lives would be changed for good. While it is true that the chemotherapy and the protontherapy would only last for a year, his health has been impacted for the rest of his life...

Hence when people ask me: "Is your son cured?", I often just do not know what to answer..."

Yes he is, from an oncological point of view: he is in remission. But we have been transformed into experts of all the possible medical specialties offered by hospitals because he suffers from a wide array of long-term side effects caused by the treatments he has received. We indeed learned the hard way that children only come last when we talk about oncology. As a result, those young beings in development are treated with adult drugs that can cause heavy long-term side effects.

As a result, our son is now closely followed by an ear, nose and throat specialist, an ophthalmologist, a cardiologist, a stomatologist, a dentist, a speech therapist, a psychomotor therapist... all of these with a frequency that can vary from every week to every six months. Which can be heavy to bear... not only does every check-up create a good deal of stress because bad news is always a possibility... but also weights on his ability to attend school, impacts his soul-searching and questioning...

Unfortunately, these constant check-ups, appointments and their related stress are also testing the psychological strength of the family cell as a whole, the brothers and sisters... who also suffered, in their own way, from the situation which caused them emotional distress and anguish.

On the bright side, we also learned from this experience some essential lessons: the value of family and of our friends who supported us without fail. But first and foremost, our children became extremely mature and apprehend life with so much joy and clarity... the other day, I was talking with a "chemo friend" about our fears for the future of our children in the current ecological and geopolitical context and our conclusion was the following: we were less worried for our own little survivors because we know that they are full of resources that no one would have imagined!

FIGHT KIDS CANCER: Let's go!

This is one of the KickCancer's achievement we are most proud of.

FIGHT KIDS CANCER is a joint initiative by KickCancer, Imagine for Margo (France) and the Fondatioun Kriibskrank Kanner (Luxembourg), the aim of which is to accelerate the most innovative treatments thanks to European financing and collaboration of research on paediatric cancers. FIGHT KIDS CANCER entails the launch of recurring annual calls for projects.

In 2020, the **first** FIGHT KIDS CANCER call for projects lead to the selection, by independent international experts, of **six innovative research projects**, from which 800 000 € are financed by KickCancer. Thanks to those projects, we hope enable major progress in the understanding and treatments of the following diseases:

- High-grade gliomas (brain tumours - 2 projects)
- Acute myeloid leukaemias
- Rhabdoid tumours
- Osteosarcomas
- Neuroblastomas

More information about these projects can be found on kickcancer.org.

The **second** call for projects is up and running and will lead to the selection of innovative projects for up to 3 million euros as well.

In Belgium, France and Luxembourg, as well as in other European countries in the future, those projects are financed thanks to the organisation of our charity family races. When more runners participate or their motivation to fundraise increases, the amount we can invest in research follows suit.

Participate in RUN TO KICK 2021 by running, walking or donating to one of your friends who participate or by sponsoring us and make kids' cancer forever frightened!





Thank you to Yves who captured the best moments of the KickCancer Challenge

KickCancer Challenge: Thierry's crazy bet to “transform a nightmare into a sunshine”

When he was attending Orvil's funerals, a twelve-year-old boy taken by a brain tumour, Thierry rolled the dice and... was plunged into a mad sport adventure with solid philanthropic and emotional ramifications... and he took the wonderful decision to involve KickCancer.

His real-life day job is director. No wonder, as a result, that Thierry succeeded in orchestrating a mind-blowing challenge and creating a strong community of kickers around his project at the pace of videos on social media where he explained his training program and his moments of emotions. Every video was an invitation to support him under the motto **“Your gifts are my fuel”**. At the heart of the lockdown, his appointments became a welcome distraction for all his followers who were turned into players of the KickCancer Challenge as they were invited to post their own “kicks” every week.

Thierry had two major aims: run across Belgium by connecting Aubange to De Panne in 9 days but also raise awareness on the need to do more research on paediatric cancers. Today, he ran the 450 km as promised and he also succeeded in fundraising 38.000 €. **What a success!** You need to hear the trembling emotion in his voice to realise that although it all seemed incredibly easy, Thierry put an impressive amount of physical and mental

preparation in order to achieve this result — with quite some aching and stiffness along the way.

Life gives back to those who give themselves because along the way, Thierry had the incredible chance to meet Elliott, a young boy in remission who became his greatest fan. He also found back the sparkle in Orvil's father's eye, his childhood friend, who accompanied him all the way across Belgium.

If you consider to start your own challenge for KickCancer, Thierry would tell you: “you are capable of much more than you would imagine provided you have the motivation. (...) If you adopt a positive attitude and rely on your own talents, things will work out by themselves quite easily”.

No more hesitation and head to our website for your own challenge team.kickcancer.org.

“The KickCancer Challenge was a fabulous gift from a friend. What made me the happiest, is the fact that through this Challenge, Orvil remained alive and we had a chance to talk about his shining personality. (...) Orvil did not want that other children suffer the way he did. So, financing research to improve the current treatments would have made a lot of sense to him.”

Aïcha, Orvil's mother

I DARE YOU TO GO THROUGH CHEMO.

Children's cancer. I donate.

kickcancer.org