

## Press Release

# Metastatic breast cancer: an ultramarathon

**Around one in every eight women will develop breast cancer in their lifetime\*. A percentage of them will be affected by an advanced form of the disease - metastatic breast cancer.**

This is what happened to 52-year old Joëlle, whose cancer came back after 14 years of remission. An enthusiastic sportswoman, Joëlle compares her cancer to an ultramarathon that requires endurance, strength and never giving up. The consequences of long-term treatment on her day-to-day life and her loved ones are onerous but often go unnoticed by others. Like many others, Joëlle also often feels forgotten because of the chronic nature of her illness. In order to ensure that breast cancer does not become a heavy, life-long burden, she is adamant that continued research is vital.

### Joëlle's story



Joëlle was first diagnosed with breast cancer 14 years ago at the age of 38. Together with her husband Philippe, she has a son, Léo, who was just six years old when she became ill. She underwent surgery, chemotherapy and, for fear of a relapse, she even decided to have both breasts removed. "I did everything I possibly could to make sure it wouldn't come back...".

The years went by, punctuated by regular check-ups. After 10 years and no symptoms, Joëlle considered herself cured. She continued to indulge her passion for sports during her treatment, setting herself challenges like the famous Marathon des Sables, a five-day footrace of 250 km through the Moroccan Sahara, which she ran in 2017.

Not only was this a sporting milestone, it was also a way for her, at the time, to mark 10 years of living breast cancer free.

But then, 14 years later, she experienced a relapse. Joëlle felt a strange sensation in her arm while running. She underwent an MRI (magnetic resonance imaging) and the diagnosis showed that the cancer had come back, this time in her brain. For her and her family, the world fell apart at that moment. This was followed by brain surgery, radiation and hormone therapy, which Joëlle continues to undergo in order to ensure that no other cancer cells are lying dormant elsewhere in her body.

### A disrupted day-to-day life and a heavy burden to bear

Joëlle has a heavy burden to bear that no-one else can see: check-ups every three months, the after-effects of the operation affecting her movements, the scars and traumas of the various treatments and operations, not being allowed to drive, the stress between MRIs, the isolation, and the worry that she may not live to see her grandchildren.

"We don't talk enough about the long-term consequences on patients' lives. After the treatments, I felt very alone, having to manage my stress and follow up with the different specialists who were each treating me separately. It's hard, and the pandemic has made things even worse.

\* Source: Globocan Report, Dec. 2020



During the pandemic, Léo would come to the hospital on his bike and stand outside in the parking lot where he could see my hospital room window (which was on the fifth floor). It was very hard at that time.

People don't realise I'm sick because I'm trying to live a normal life. But I know I'm not out of the woods yet, it's there, it can come back anytime. After the operation, you are 'fine' but you don't feel any better. There is a risk of further relapse and you have to be able to manage this burden. Metastatic breast cancer is like an ultramarathon, you are in it for the long haul. You have to be vigilant, and take care of yourself and your body," Joëlle confides.

## We need further research

Despite the enormous progress already made in early-stage breast cancer, metastatic breast cancer is still an incurable disease that affects many patients. And while some patients live longer than others with the disease, we still don't understand why.

To mark Pink October, researchers from the *Breast International Group (BIG)*, supported by *BIG against breast cancer*\*\* are sounding the alarm. There is an urgent need to find better treatments for these patients and, to do so, further research and funding is required.

"We have definitely come a long way. Most women with breast cancer are now able to get through it because they are receiving increasingly targeted treatments. There is a public perception that this disease is almost under control, which is not true. The progress mostly concerns early-stage breast cancer. Once the cancer spreads to other organs or recurs, we doctors have far fewer options for our patients. It is our duty to carry out further research. It's vital," stresses Dr Martine Piccart, co-founder of the *Breast International Group* and President of *BIG against breast cancer*.

## Pink October 2021: Together we will cure breast cancer

Inspired by Denis Korrman\*\*\*'s *Legend of the Hummingbird*, the Breast International Group, supported by *BIG against breast cancer*, has chosen this formidable little creature to represent its work dedicated to curing breast cancer.

The tale of the hummingbird goes as follows:

*One day, in a forest somewhere, an enormous fire was raging. All the animals were terrified, running around in circles, screaming, crying and helplessly watching the impending disaster.*

*But amid all this, over and over, the tiniest little hummingbird was flying from a small pond, collecting drops of water in its beak, and dropping them on the fire.*

*The other animals watched the little creature incredulously and asked it, "But why are you doing this? Your little drops of water won't stop the fire!". To which the hummingbird replied, "Could be, but I'm going to do my bit." This act of heroism and selflessness inspired the other animals, who in their turn started picking up droplets of water and putting them on the fire. Eventually, with the dedication, perseverance and teamwork of the animals, the fire was extinguished.*

\*\* Research projects conducted by BIG are supported in part by its philanthropic unit, *BIG against breast cancer*, which solicits funds from the general public and donors in order to support clinical studies and academic research programmes piloted by BIG.

\*\*\*<https://www.youtube.com/watch?v=zbv3CoRH29o>



The *Breast International Group (BIG)* is the world's largest network of academic research groups dedicated to breast cancer research. Much like the animals of the forest, BIG's researchers work tirelessly together each day to advance research more rapidly and thereby contribute to improving and saving the lives of women and men affected by the disease. Together, we can cure breast cancer, drop by drop.

Roseline d'Oreye, a famous Belgian artist, has joined forces with *BIG* to create a unique hummingbird design, which will illustrate the campaign and future activities of the network.

### **AURORA: the “Metastatic breast cancer GPS”**

The *Breast International Group* is the initiator of the European research programme AURORA, also known as the “metastatic breast cancer GPS”, which aims to better understand how and why breast cancer returns - sometimes years later - and spreads to other organs.

Researchers aim to decipher the growth of the cancer cells through extensive genetic testing of the primary tumour (located in the breast), on metastases and in blood samples. Armed with this knowledge, they hope to stop these cells from developing and spreading by identifying the best possible treatment.

More than 1,100 patients are already participating in this large-scale programme and the initial results are very encouraging.

**For Joëlle, as for many patients living with metastatic breast cancer, the AURORA programme offers the hope of better understanding why the disease comes back and to be able to anticipate it.** “Because cancer will come back for some women, like me, we need to be able to offer effective treatments in the future and stop the disease from spreading,” Joëlle points out.

”Understanding why some breast cancers recur and spread while others are cured is paramount to developing treatment strategies that will boost recovery rates. AURORA aims to address this goal through an advanced molecular analysis of a sample taken from the breast tumour and a sample taken from another organ. We hope that this international study will be a major contribution in the fight against this disease,” says Dr Philippe Aftimos, Co-Principal Investigator of the AURORA programme and Clinical Trials Development Leader at the Jules Bordet Institute in Brussels, Belgium.

In spite of the difficulties she faces due to her illness, Joëlle has continued to stay fit and participate in sporting events for fun. Last July, she ran the Al Andalus Ultimate Trail (AAUT) in Andalusia (230 km in five days) with her son Léo. Together they raised EUR 2,500 to support AURORA and research on metastatic breast cancer.

Thanks to her courage, resilience and positive attitude, Joëlle has been able to rise up to all of these challenges until now. This is possible also thanks to treatments and advances in research, of course.

**In order for all patients to continue to face the challenges of life without having to bear the burden of breast cancer, further research needs to be carried out.**

## Let's fight metastatic breast cancer together

Throughout the month of October, BIG is hosting a series of events and lectures to raise awareness of metastatic breast cancer.

*Wednesday, 29 September*

Press conference to launch Pink October month

*Wednesday, 6 October*

talk given by Dr Martine Piccart and organised by L'Eventail magazine (Salle Flagey, Place Flagey, 1050 Brussels)

*Wednesday, 13 October*

Webinar for the general public on "I have Metastatic Breast Cancer: what is my future?"

Thursday, 28 October

Tête en Fête Pink is the new black ball (Acte 3, Clos Lamartine 1, 1420 Braine-l'Alleud)

### Some key dates:

October is breast cancer month.

*Thursday 7 October*

International Male Breast Cancer Awareness Day.

*Wednesday 13 October*

International Metastatic Breast Cancer Awareness Day

**For more information about Breast International Group's clinical trials and research programmes, or regarding events or interviews, please contact:**

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### About Breast International Group (BIG)

The *Breast International Group (BIG)* is an international not-for-profit organisation for academic breast cancer research groups from around the world, based in Brussels, Belgium.

Global collaboration is crucial to make significant advances in breast cancer research, reduce unnecessary duplication of effort, share data, contribute to the faster development of better treatments, and increase the likelihood of cures for patients. Therefore, BIG facilitates breast cancer research at international level, by stimulating cooperation between its members and other academic networks, and collaborating with, but working independently from, the pharmaceutical industry.

In 1999, BIG was founded by Dr Martine Piccart and Dr Aron Goldhirsch with the aim to address fragmentation in European breast cancer research. Research groups from other parts of the world rapidly expressed interest in joining BIG and, two decades later, BIG represents a network of over 50 like-minded research groups from around the world. These entities are tied to several thousand specialised hospitals, research centres and world-class breast cancer experts across approximately 70 countries on 6 continents. More than 30 clinical trials are run or are under development under the BIG umbrella at any one time. BIG also works closely with the US National Cancer Institute (NCI) and the National Clinical Trials Network (NCTN), so that together they act as a strong integrating force in the breast cancer research arena.

BIG's research is supported in part by its philanthropy unit, known as BIG against breast cancer. This denomination is used to interact with the general public and donors, and to raise funds for BIG's purely academic breast cancer trials and research programmes.

For more information, visit [www.BIGagainstbreastcancer.org](http://www.BIGagainstbreastcancer.org)

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