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Risk and investment must be shared, and paediatric development needs to become a default part of innovation, not an afterthought

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Born from personal tragedy, Imagine for Margo has evolved into a pan-European force reshaping how childhood cancers are researched, funded, and brought to the policy agenda. Drawing on a parentâ??s perspective, Patricia Blanc explains how precision medicine, cross-border collaboration, and sustained advocacy can compress timelines and reduce inequality in rare paediatric cancers. She also makes a clear case for why the next phase depends on deeper public and industry engagement.

What led you to create Imagine for Margo, and how has that experience shaped the associationâ??s mission today?

I am the President and co-founder of Imagine for Margo â?? Children without Cancer, which I created with my husband in 2011 after losing our daughter, Margaux, to an aggressive brain tumour. She was diagnosed in 2009 at the age of 13 and fought the disease for around 16 months. During that time, she launched an appeal that raised more than EUR 100,000 for paediatric cancer research. That initiative became the starting point for everything we later built.

Before this, my husband and I had spent nearly 20 years working in audit and international finance, with no connection to the medical world. Like many parents, we did not even know that children could develop cancer. When Margaux was diagnosed, we were told very quickly that there was no curative option. She was treated with chemotherapy protocols developed for adults, some of which were not specifically authorised for children. What struck us most was not only the absence of options, but the realisation that these were essentially the same treatments that had been used for decades, despite the aggressiveness of childhood cancers.

At that time, childhood cancer was already the leading cause of death by disease in children over one year old in Europe and in the United States, yet access to innovation remained extremely limited. Paediatric cancers are rare and fragmented across more than 100 different diseases, which has long slowed research and discouraged investment. Adolescents like Margaux were particularly overlooked, often falling between paediatric and adult treatment frameworks, with very limited access to clinical trials. We spent months searching for alternatives across Europe and the United States. There were none, not because the science did not exist, but because it had not been developed for children. That sense of injustice was impossible to accept.

Imagine for Margo was created with a clear purpose: to accelerate research, to give children and adolescents access to innovation, and to ensure that other families would not face the same absence of options that we experienced. From the outset, our priority has been to finance research, with a deliberate decision to act at European level, not only in France. In rare paediatric cancers, progress depends on pooling patients, expertise, and data across borders. Without that scale, innovation simply moves too slowly.

Our work is structured around four pillars. First, funding innovative research at European level. Second, awareness and advocacy, because in 2009 childhood cancer was largely invisible to the public. Third, mobilisation, bringing together researchers, clinicians, industry, patient organisations, and public authorities. This collective approach reflects my previous experience in international finance, where impact depends on coordination. Finally, we remain close to children and families, supporting daily life in hospitals and offering activities and support for parents alongside medical care.

Awareness remains a critical challenge. The gold ribbon, the international symbol of childhood cancer, is gaining visibility, but it is still far from the recognition achieved by other causes such as breast cancer. September is recognised globally as Childhood Cancer Awareness Month, often referred to as Gold September, and coordinated internationally by Childhood Cancer International. At Imagine for Margo, we focus on awareness that leads to action. From the beginning, we organised large public events, particularly fundraising races inspired by models in the United States and adapted in France and across Europe. We also work collectively in France, including through initiatives such as Collectif GRAVIR, and support symbolic actions like lighting monuments in gold to bring childhood cancer into the public space. Progress is real, but it remains insufficient. Awareness has improved, yet it still does not reflect the scale or urgency of childhood cancer. That gap continues to drive everything we do.

How has Franceâ??s oncology research ecosystem translated into concrete progress for children with cancer, and where do you see both its strengths and its remaining limits today?

From a patient perspective, France has made tangible progress in paediatric oncology, particularly in research and precision medicine, even if important gaps remain. Innovation in oncology is strong in France overall, and for children this has first translated into a much deeper understanding of disease

biology. The question parents inevitably ask is why their child has cancer, and answering that requires understanding why some children respond to treatment while others relapse or develop resistance. Because paediatric cancers are not a single disease, but more than 100 rare and fragmented conditions, large-scale molecular profiling has been essential to move beyond uniform treatment approaches.

A major turning point came in 2016 with the launch of MAPPYACTS, coordinated through leading paediatric oncology centres with Gustave Roussy as a central hub. The programme focuses on children and adolescents with relapsed or refractory cancers and uses high-throughput molecular analyses of tumours and leukaemias to guide access to innovative therapies and clinical trials. Supported by both public and philanthropic funding, including INCa (the French National Cancer Institute) and partners such as Imagine for Margo and Fondation ARC, MAPPYACTS helped make precision medicine operational in paediatric oncology. Its integration into the France MÃ©decine GÃ©nomique 2025 initiative reflects a broader national shift towards embedding genomic medicine more systematically in care and reducing inequalities of access across the country.

In parallel, we helped initiate AcSÃ©-ESMART, a one of a kind precision-medicine trials in paediatric oncology wordwide. Designed for children and adolescents in relapse or therapeutic failure, this early-phase, multi-arm platform trial uses molecular profiling to match patients to targeted treatments within a single adaptive framework. New treatment arms can be opened rapidly and closed early if they show no benefit or raise safety concerns, which shortens timelines, improves safety, and avoids exposing children to ineffective therapies. This unique model has accelerated access to innovation and has become a reference framework at European level.

Another important step was the creation of SACHA, which addresses situations where children cannot access a clinical trial despite the availability of innovative medicines. Coordinated through Gustave Roussy and supported by ANSM (the French medicines agency), SACHA is a prospective observational registry that collects real-world safety and outcome data when anticancer therapies are used outside clinical trials. It secures access while ensuring structured follow-up and pharmacovigilance, and it generates evidence that can later support the launch of formal trials. What began as a national initiative has since expanded internationally, reflecting the need to pool data in rare paediatric cancers.

France has also played a leading role in research on particularly aggressive diseases, such as DIPG (diffuse intrinsic pontine glioma), a brain tumour with a devastating prognosis. Through international programmes such as BIOMEDE, molecular profiling and adaptive trial designs are being applied to better understand these tumours and test new strategies across multiple countries, because progress in such rare diseases depends on collaboration and shared data. Despite these advances, this is still only the beginning. In fact, today in France, eight children are considered â??long-term survivorsâ?• of this type of cancer. Our commitment to supporting research at the European scale, alongside the ITCC network and through the creation of Fight Kids Cancer, has indeed offered European scientists the opportunity to innovate as never before. The BIOMEDE and BEACON programs exemplify this vision. Our significant financial contribution to the BEACON program has made it possible to progressively improve therapies for relapsed neuroblastoma, a cancer affecting young children. By optimizing first-line chemotherapy and combining it with immunotherapy, the life expectancy of children with relapsed neuroblastoma has progressively increased to up to 40%, representing an important step forward. Theses two leading programs show that infrastructure, data, and clinical frameworks are now largely in place, but the next challenge is to translate this knowledge into new medicines and to attract far greater industry engagement. While interest has improved, paediatric oncology remains under-prioritised by big pharma and also by biotechs and startups where much innovation originates. Creating the right incentives, reducing administrative burden, and accelerating access pathways will be essential if this ecosystem is to deliver fully for

children.

In that context, initiatives such as the Paris-Saclay Cancer Cluster are encouraging. Launched in 2022, it brings together major oncology actors and has established a dedicated Childhood Cancer Working Group, signalling that paediatric oncology is starting to be treated as a genuine innovation space rather than an afterthought. Our involvement in Hack4Hope, a hackathon designed to connect startups, clinicians, researchers, industry experts, and patient organisations, reflects the type of bridge that now needs to be built. These initiatives alone are not sufficient, but they point clearly in the right direction. If children are to benefit from the next generation of therapies, this is the level of coordination and ambition that must now be scaled.

How has France strengthened the patient pathway and diagnostic infrastructure for children with cancer?

When we talk about early diagnosis in paediatric oncology, it is important to be precise. This does not mean that childhood cancers are detected earlier at population level. What has improved substantially is what happens once a child enters the care pathway. France now has far more systematic access to molecular characterisation, including next-generation sequencing, which allows diagnoses to be refined and treatment decisions to be better guided, both at relapse and, increasingly, from diagnosis depending on the tumour type and clinical context.

This has also reduced inequalities of access. France has put in place structured national and interregional networks so that decisions are not driven solely by geography. Multidisciplinary paediatric oncology tumor boards and shared expert discussions mean that children treated outside major reference centres can benefit from the same level of expertise as those cared for in large academic hospitals.

These clinical improvements are supported by national infrastructure. Centralised sequencing capacity has been developed through the France MÃ©decine GÃ©nomique plan and a broader tumour molecular genetics network supported by INCa, enabling more consistent genomic testing and interpretation across the country. Access to innovation is further reinforced through CLIPÂ²-labelled early-phase trial centres, which are accredited structures for phase I and early phase II oncology studies. Some include paediatric activity, offering children safer and more structured access to early innovative treatments when standard options are limited.

How do you assess the current level of government engagement in supporting paediatric oncology, in France and at European level?

From a patient perspective, there has been tangible progress in France, particularly in public funding dedicated specifically to paediatric cancers. A first milestone came at the end of 2018, when patient organisations secured a ringfenced allocation of five million euros per year for fundamental research in paediatric oncology. While this amount remains insufficient, it sent a clear national signal and, importantly, it has been renewed year after year. Governance has also been key. Working with INCa alongside other patient collectives, we help define priority research areas so that these resources are channelled towards high-impact topics in childhood cancers, which has helped strengthen the basic research pipeline. More recently, political commitment has expanded. Parliament approved an additional fifteen million euros for paediatric cancers research in 2025, and there have been active discussions around securing more sustainable funding for clinical and fundamental research through a dedicated 20 millions annual budget line. This is still an early phase, but it reflects growing

recognition that paediatric oncology requires clearer, more visible, and more predictable public support.

At European level, two policy developments have been particularly important. Europeâ??s Beating Cancer Plan, published in 2021, marked the first EU-wide framework addressing the entire cancer pathway and includes a dedicated flagship for children, reinforced by the European Parliamentâ??s recommendations through the BECA committee. In parallel, Horizon Europeâ??s Mission on Cancer explicitly recognises childhood cancer as a transversal priority, enabling funding mechanisms that support research and coordination across borders. National action remains essential, but real acceleration depends on sustained European engagement. With competing priorities at EU level, continued funding for paediatric oncology cannot be taken for granted, which is why we remain closely involved, alongside other parent organisations, in monitoring and advocating for these commitments.

How do you assess current industry engagement in developing new therapies for paediatric oncology, and what is still missing?

At this stage, industry engagement in paediatric oncology remains largely insufficient. While innovation in oncology is extremely active among biotechs and startups, the focus is still overwhelmingly on adult cancers. The primary driver is economic. Adult indications offer larger patient populations and clearer business models, so new technologies and molecules are developed there first. There is also a significant knowledge gap. Many startups are unfamiliar with paediatric oncology, its clinical specificities, and the way the ecosystem functions, and in some cases childhood cancer is simply not considered at all. When we speak with young biotech teams, many are genuinely surprised to realise how limited therapeutic development still is for children. Once they understand the reality, interest often emerges, particularly among a generation that is looking for purpose and impact in what it builds.

This is where patient organisations have an essential role. We help connect innovators with clinicians, researchers, and families, clarify unmet needs, and support the adaptation of technologies to paediatric contexts. That can also involve helping identify funding pathways and think through business models that make paediatric development viable. Initiatives such as Hack4Hope are encouraging because they create direct dialogue between startups and the paediatric oncology community, but they remain early steps. Overall, we are still far from the level of industry engagement that children need, and closing that gap will require stronger incentives, clearer frameworks, and more coordinated support.

How has Imagine for Margo built impact at European level, and what underpins your approach to accelerating progress in childhood cancer?

From the beginning, we understood that childhood cancers are rare, highly fragmented, and driven by urgency. Acting in silos does not work when children do not have time to wait, which is why we chose early on to operate beyond national borders and to focus on coordination and scale. We started by mobilising funding in France to move research faster than the system could on its own. Since 2011, we have allocated around thirty million euros to paediatric cancer research in France and across Europe, supporting translational and clinical projects and enabling children to access innovative approaches through the programmes we co-finance. We have been deliberate in how we deploy resources, prioritising initiatives that change how the field functions rather than funding research in isolation. This includes precision-medicine programmes such as AcSÃ©-ESMART and

MAPPYACTS, which have helped make molecular profiling and adaptive trial designs more systematic and actionable.

This approach reflects a parentâ??s perspective. Parents ask direct questions. Why does one child respond while another relapses. Why do trials take years to open when children do not have years. That urgency pushes different ways of working, with faster trial structures, better coordination, and shared data. At the same time, we quickly realised that philanthropy alone will never be enough. That conviction led us to help build Fight Kids Cancer, a European model that pools funding across countries to support larger and more ambitious research programmes. By working with other parent organisations and a shared scientific governance framework, this initiative has already mobilised more than forty million euros for paediatric oncology research and continues to grow. Pooling resources allows us to support early-phase trials and cross-border programmes that single-country philanthropy cannot sustain on its own.

Ultimately, this also underpins our advocacy. Private funding will never be sufficient in isolation. Improving outcomes at scale requires sustained public investment and stronger industry engagement, from large pharmaceutical companies as well as biotechs and startups. The objective is clear. Risk and investment must be shared, and paediatric development needs to become a default part of innovation, not an afterthought.

How are you preparing the next phase for Imagine for Margo, and what priorities will guide your work in the coming years?

The year 2026 marks fifteen years since Imagine for Margo was founded, and we want this milestone to be more than symbolic. It is an opportunity to clearly document our impact, to be transparent about what has been achieved and what still needs to change, and to use that evidence to drive the next phase of acceleration, particularly in research and industry engagement. As part of this process, we will publish a comprehensive impact report in early 2026.

Our priority going forward is sustainable growth. Long-term, predictable funding is what allows researchers to build programmes, recruit teams, and move faster, rather than spending a significant share of their time searching for resources. Through our European collaboration Fight Kids Cancer, we have demonstrated that this approach works. Since its launch in 2020, the initiative has scaled steadily, reaching twelve million euros allocated in a single year in 2025, with more than forty-two million euros committed to forty-six research projects by September 2025. Our next objective is to exceed fifty million euros allocated to childhood cancer research, because pooled, multi-country funding reduces inequality, accelerates trial activation, and gives researchers the confidence to plan for the long term.

Beyond funding, the central challenge is to establish a new model for paediatric oncology that fully integrates public authorities and industry. This requires incentives from governments, faster regulatory and administrative pathways, earlier dialogue on value, and a shared approach to risk and investment. We are now at a point where this is realistic. We have data, we have precision medicine, and we know that many molecular targets are shared between adult and paediatric cancers, which removes any scientific justification for delaying paediatric development for many years.

This is why regulatory reform remains essential. Europeâ??s paediatric medicines regulation was designed to ensure children benefit from innovation, but it has not delivered for paediatric cancers. The ongoing revision of EU pharmaceutical legislation offers a real opportunity to correct this, by creating clearer expectations and stronger incentives to study relevant oncology medicines in children earlier. The direction taken in the United States with the RACE for Children Act shows that a

more ambitious approach is possible, and discussions around a European Biotech Act also matter, because if innovation is to include children by design, the broader biotech ecosystem must support that ambition.

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