Nothing can stop happiness



# EVERYDAY HEROES

A FILM BY ANNE-DAUPHINE JULLIAND
THE AUTHOR OF "TWO SMALL FOOTPRINTS IN WET SAND"

IN FRENCH THEATERS ON FEBRUARY 1st 2017

TF1

## **SYNOPSIS**

EVERYDAY HEROES is a feature length documentary about the power of life and resiliency. The documentary features five children who are willing to share with us their everyday life, their doubts and their joys.

These children among all children have a particularity. Imad, Ambre, Charles, Tugdual and Camille have been diagnosed with serious pathologies, which make them both very mature and self-aware of the power of now. But above all, they remain children.

Anne Dauphine Julliand, the director, has been able to capture the decency and innocence of these amazing kids, who really stand among every day heroes, and share with us a lesson of life. We believe this movie is made to change preconceived ideas, upon life, childhood, resiliency and the power of now.



## **DIRECTOR'S INTENT**

Some encounters change the course of your life. The documentary film **Et Les Mistrals Gagnants** was born of such encounters.

The very first one of these encounters is Thaïs. Thaïs, my daughter with her princess name, who suffered from an deadly illness with a barbaric name: a metachromatic leukodystrophy.

When she was only two years old, Thais opened my heart and taught me to appreciate every single moment of existence. I came to realize that a beautiful life is not measured by the number of its years.

Over time, I met a number of families impacted by the illness of a child. They opened my eyes. Again, I witnessed the power of children's lightheartedness. I understood the extent to which their vision of life can alter our own. I wanted to share this with as many people as I could. I wanted to tell that story, to show it in an irrefutable way: through the words and perceptions of children.

The project took a huge step forward when I met French producer Édouard de Vésinne. He was immediately taken by the idea of the film. His enthusiasm convinced me of the topic's universality. It doesn't resonate only with those who have personally experienced this - it finds an echo in each and every one of us through intuition, a perception of life that we are all familiar with because we've all been children, capable of simply loving life.

The film then started taking shape through encounters with precious allies, those unavoidably responsible for the children's care: hospital wards, palliative care units, in-home healthcare professionals, nonprofit organizations supportive of sick children and their families. They trustfully opened their doors to us, because the film's subject matter is the reason behind their work and commitment: to add life to days, every day. They accompanied us through the project's most beautiful encounters. Those with the brave, fighting, living hearts of the documentary <code>Et Les Mistrals Gagnants:</code> the children.

It is so moving to see how fast these children integrated us into their worlds, inviting us with great simplicity to share their best times as well as their most difficult moments. Over the course of the shoot, we got to know each other, as in Saint-Exupéry's *The Little Prince*, by "creating bonds" that enabled us, each day, to "sit a little closer". And once we reached that close proximity, we placed ourselves on their level, figuratively and literally, in order to record their words. A most precious gift.



## INTERVIEW WITH ANNE-DAUPHINE JULLIAND

#### One can imagine that this is not a film into which you ventured by accident.

It started with a personal experience. Life takes us on unexpected journeys. I had a little girl who was very sick and died from this illness. An ordeal no one wants to live through. Starting with me. And yet, through her experience and the way she lived her life, I discovered another way to live my own. I sort of reconnected with my inner child and re-learned how to only concern myself with what is happening in the moment. This helped me tremendously to get through my grieving process. And to simply live my life. I started out by writing a book about what I went through: **Two Small Footprints in Wet Sand**. I realized that what I experienced was the essence of childhood. There was nothing extraordinary about my daughter, she was just a kid who faced a difficult situation and learned to manage it. But that didn't prevent her from loving life. So it occurred to me that I had to show this in a different way. Above all, I had to let the children speak for themselves. That is how the idea for this documentary came to me, as the only way I could give them back their voice.

#### Did this film take time to prepare?

Of course. And I wanted to take my time. To meet the children one after the other. Obviously this was no casting. I sought out a trusted network of healthcare professionals in the psychosocial fields. My project would bring to their mind children they helped or cared for. They then contacted their families and presented them with the film project. Once the parents agreed to get in contact me, I met the children. Seeking equilibrium, we shot each story one after the other. Our intent was to strike a balance between the various personalities, social, geographical and personal medical situations, in order to reach something as all-encompassing as possible.

#### How did you manage to convince a producer to get onboard with the project?

By offering to make a film about life. Because that's what this film is about! Life seen through the eyes of children. I could have made a similar film with healthy children, as the film's theme is not their illness. But being confronted to it makes it that much more powerful. When an adult's daily life is shattered by a huge ordeal, everything is thrown into turmoil. Not so for a child. That is the great difference between us.



## What is striking in the way these children express themselves is their lucidity. The way they master a very precise language...

That is one of the things that struck and amused us. They use words like neuroblastoma, which most people don't know and are very lucky not to have as part of their vocabulary. It is part of these children's but they use these words without drama. They're quite proud of knowing complicated words and at the same time, when using them, they make kid language mistakes. One of them keeps misspeaking every time he uses some these words, he speaks of "concert" when he means cancer, and of "tuner" for tumor. As though wanting to distance them from their life. Like knowing that is part of their existence but not wanting it to.

## You film a consultation during which the parents seem to stand back while the child leads the conversation, without fear.

Many parents explained to me that their child took them by the hand. How, in the heart of these tragic, desperate situations, they saw their children move forward in life and how fathers and mothers ended up following the lead of their child.

#### The film also follows their footsteps and their way of facing life.

We chose to film at the children's level, listening only to them and respecting their rhythm. Including in the editing process. The film is actually just an appreciation of their daily life. They will cry in pain and two minutes later laugh

and criticize their mom for putting too much salt in the food. They live in the present moment. I wanted the film to have that kind of beat.

#### You focus on life above all else. Without ever watering anything down.

There is a reality to capture. We knew there would be difficult moments, whose limits would be set by our sense of propriety and our decency. There were also some things we did not want to go through. For instance, there was no way I was going to film Charles' bath. He bathes about every three days, and that bath was planned during the time we had with him. But he was the one who invited us to witness it. I wanted to refuse on the pretext that I wanted to leave him be in this moment, give him privacy. But he replied that if I didn't film him in his bath, there was no point in filming him at all. The bath is a part of his life! And all of a sudden, he made us understand that we shouldn't be afraid of his daily life. That if we got close to him, we couldn't pretend. By doing this, he liberated us from a fear we had and enabled us to film that scene, which is not an easy one. And – I hope – we found our place. It was something all the kids who participated in the movie had in common: they all encouraged us to go all out, to not tone down the difficult moments. They all wanted us to film them at the hospital, because it is a part of their life.

## But in order to manage that, do you have to, at a certain point, force yourself, overcome your sense of propriety?

Of course, because propriety is a way we conceal our fear. So yes, there were many things we had to overcome. For the sake of the entire crew. I probably had an awareness of certain difficulties that the director of photography or the sound engineer didn't. It was a collective experience, full of sharing, of conversations and exchanges. It impacted our lives and revealed many things about ourselves. The way each of us approached the film and the subject matter reassured me about the direction we chose. But one important thing needs to be mentioned: we also shared great moments of laughter and levity with the kids.

#### What of the medical staff's involvement?

We asked them to trust us. I think the medical staff wanted this film to exist. I remember meeting a pediatric nurse, someone in daily contact with illnesses that gravely impact children. She told me that she was often asked how she manages in the face of so much pain. But going to work every morning, she knew she wasn't going to confront illness but rather courage, strength and resilience. All that is what motivates her. I wanted the film to give a sense of what the medical staff goes through every day. Which is probably the reason why they welcomed us so warmly.

## We see their work as well, day after day. The gestures that sometimes appease their powerlessness. And also their reassuring words.

And that is amazing to behold. When I see nurses – mostly women – or teachers adapting to the children, each in their own way, I am bowled over by so much grace. They are not at the heart of the film but I wanted to give them a place because they are part of it all. Their attitude, the way they look at the child, help the kids position themselves in life and in society. They have their place in the film without ever being at the center of it, because I like to only see their hands, their gestures in the frame. At one point, one of the children climbs down from an examination table and you just see the doctor caressing the back of the kid's head. I think it is one of the most beautiful gestures in the film and it says so much more than anything the adults and medical personnel could have told us. It is a gesture that also expresses the bond that exists, their deep understanding of the child they're caring for... I think this humanity is not shown enough and I wanted to bear witness to it.

## Let's talk a little about the way you directed the film. Because there is an undeniable direction in your film. How many cameras did you use?

Just one. I was lucky to have very athletic camera operators (laughter). First of all because we wanted to be the lightest, most unobtrusive film crew possible, even though we never asked the kids to act as though we weren't there. We wanted to make sure that whatever was given to us was consented to. Also, I told myself that with just one camera we wouldn't be everywhere and that specifically felt important to me. Important because it determined a point of view, a choice. And if the child wanted to move or leave the frame, he/she was free to do so. It was a way to respect his/her freedom. I didn't want to pick up his/her movement with another camera. I specifically didn't want him/her to feel cornered. The child had to know who he/she was talking to, as though the camera were a spectator.

## There is no theorized desire to direct, to frame and yet every shot has its stage direction. In other words, this brings up the question of distance.

I would rather simply coin that as proximity. You have to face the topic of sickness. From too far away, you can't get into it. Too close and it becomes indecent. The camera operator and I talked it over at length. The true question is feeling. And that goes through talking about it and taking into account the child's attitude. Some step forward, others stand back... The camera's place, the one that feels right to us, has to go through all that. It's intense because we and the frame have to be reactive, because a child moves, evolves and changes attitudes all the time.

## We see them at the hospital, at home but also outside, taking part in activities that reflect who they are - in a theatre class, at a fire station, in a shipyard - moments when they project a future, careers they might like to have.

Yes, simply because that is life. Their life. We filmed without really expecting anything. Which wasn't always easy for the crew. I wanted to follow the child. Do what the child wanted us to do together. I even found myself dressed up as a princess (laughter). We wanted to find out what was important to them and go there together. For Ambre, it was theatre, performing, her dress rehearsal. Tugdual wanted to show me his garden, his plants. We alternated between very simple things and others that were, on the contrary, exceptional, like the boat scene with little Charles in that gigantic ocean liner. I had plenty of intentions. But I preferred to follow them. And as a result, we went much further than what I had imagined.

#### Was the editing, a most crucial stage if ever there was one, particularly delicate?

Indeed, the editing process was pointed and delicate. I worked with two editors and each of them brought a know-how. What was complicated was that we arrived at five stories shot in five different locations with a single driving theme, which was childhood. It would have been easier to remain in a single place, stick to one pathology. So we had to create coherence, give the impression that the children knew each other - which was not the case, they met after the shoot – and responded to one another. Striking that balance required a lot of work and we spent five months editing, perched on that somewhat dodgy cusp where the slightest misstep could have proved fatal for the film.

#### More than for any other film, finding a way to wrap up and end Et Les Mistrals Gagnants must have been challenging.

It was complicated because this film's great difficulty - which may seem paradoxical – was its simplicity. So how to end it? I had that shot on a beach, which I found beautiful but at the same time I wanted to avoid a pretentious ending,





which would have felt wrong. It had to be as simple as what the children gave us. It's just their life. We rang their doorbell and they invited us in, then we left. We say goodbye. I didn't want that goodbye to sound like it was forever. I didn't want a false sense of drama. I tried to remain true to simplicity and exit on an image that replenishes the heart.

#### The title refers to a song by French singer Renaud, which plays at the end of the film...

That song was with me from the start of the project. One day I realized that each time I started writing, I would hum Et Les Mistrals Gagnants. I realized that Renaud's song all on its own synthesized the film's entire theme. The film isn't "Let me show you what a sick child looks like" but rather: "I want you to remember what it was like to be a little kid. That lightheartedness." It is specific to childhood, we've all felt it. And I believe this wisdom we all seek to acquire as adults is nothing but that lightheartedness. The promise of life. While being acutely aware that childhood isn't easy, that there are tears, there is pain...

#### It is the only music in the film that refuses sprucing up, or anything that might minimize what we see on screen.

I hesitated to play it. But I wanted a moment when the film released the tension inherent to it. For there to be a moment when the viewer gets a bit more deeply ensconced in his/her seat and is able to watch with interiority as these children live their lives, only to later recapture us, as if to say "come on, let's keep on going."

#### Do you intend to show the film to the kids?

They've seen it. All together. And to me, it was probably the most stressful screening, the most important and the most moving. Because they are the most demanding audience! What I can say is that they saw themselves and recognized themselves. Without necessarily focusing on the moments when they were onscreen. It felt as though they were attentive to each other. And above all, they recognized what links them together. And I think they were happy to have shared all that together.

## THE CHILDREN



Like many boys his age, Camille's passion for soccer expresses itself all over the walls of the bedroom he shares with his older brother. He belongs to a soccer club in his town outside Paris, and would never miss practice with his daddy.

On the soccer field he runs, dribbles, attacks, tries harder and pushes his limits. Limits imposed by his condition. "Neuroblastoma, that's my sickness, neuroblastoma", he explains. A sickness that, ever since he was very little, has given him no respite. But Camille knows how to bounce back, adapt, and keep smiling at life.



She never removes her little Tinkerbell backpack. Never. Not out of coquettishness - and lord knows Ambre is as girly as they come - but because she needs it to stay alive. The little pink bag contains a pump connected to her heart.

Amber has a serious heart condition. "I shouldn't do sports but I do anyway because I love life" she says with a smile. Yes, Ambre loves life! And the love of life she exudes is incredibly powerful for a nine-year old girl.



There is something intriguing and captivating in Tugdual's eyes. Something indefinable at first, before one takes a closer look: one of his eyes is green, the other is brown. Different-colored eyes but not since birth. Tugdual explains how they became that way after a surgery to remove the tumor lodged against his aorta, when he was three.

"A tumor this big" he explains, forming an alarmingly large circle with both hands. Tugdual just cheerfully celebrated his eighth birthday. An exceptional birthday, with more friends than he could have imagined.



He talks with his hands and a slight accent, reminiscent of how far he's come. From his six-year-old perspective, Imad tells his story, using words that a kid his age normally doesn't know. Words that life has taught him.

He talks about severe kidney failure, dialysis, hope for a transplant "even though it's risky". He remembers his hometown in Algeria, which he left in a hurry two years before, to come to the unknown country of France and be treated. He recalls with stars in his eye when he "flew in an airplane".

That rushed maiden flight might have been what has struck him the most. A child's dream come true. Because beyond his maturity and his little man demeanor, Imad remains a regular little boy.



The hallways echo with the laughter of Charles and his buddy Jason. We let ourselves be guided by the mirthful sounds until we find their source. But the moment we locate them, the boys run off again, laughing even harder, defying us to catch up. The two friends know every nook and cranny of ESEAN, the children and teen healthcare facility where Charles spends his weeks. On weekends, he goes home to his parents and his big brother.

In order to be treated, it is essential for him to live in a hospital setting. His daily care is lengthy and arduous. It involves treatment of the sores that cover his entire body. Charles suffers from a terrible illness: epidermolysis bullosa. "My skin is as fragile as butterfly wings" he tells us.

Charles is well aware of his frailty; he is also cognizant of his strength. The strength of a nine-year old little boy who understands better than anyone the meaning of the word courage. And who knows how to share it. Charles was lucky enough to fulfill his childhood dream, thanks to the amazing work of the nonprofit organization *Petits Princes* (Little Princes), a dream we were able to film with great emotion and pleasure.



## BIOGRAPHY OF ANNE-DAUPHINE JULLIAND

### WRITER / DIRECTOR

Anne-Dauphine Julliand was born in Paris in 1973. After obtaining her Baccalaureat, she studied journalism. She wrote for daily newspapers, then for the specialized press.

In 2006 she finds out her second child, Thaïs, 2, suffers from an incurable degenerative illness: metachromatic leukodystrophy (MLD). Her life expectancy is very short.

In March 2011, Anne-Dauphine Julliand published *Two Small Footprints in Wet Sand*, in which she shares the experience surrounding the illness and death of her daughter Thaïs. The book sold over 350,000 copies in France and was translated in more than 20 languages.

In June 2013, she published **A Special Day**, the story of her family four years later, which sold over 60,000 copies in just a few months. After being elected to the board of directors of ELA (European Leukodystrophy Association), Anne-Dauphine Julliand is now a member of the scientific committee of the **Palliative Care Fund**.





#### International Book Covers of Two Small Footprints in Wet Sand:









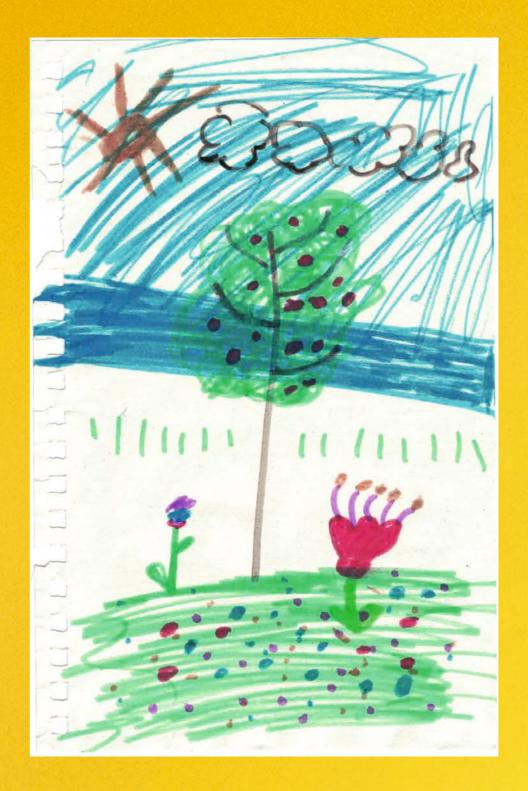




# **PRODUCER**INCOGNITA FILMS

Since 2002, **Édouard de Vésine** has produced over 50 movies, series and feature films for Incognita Films, Europacorps Television and Cipango Films.

**Et Les Mistrals Gagnants** is his first feature-length documentary for the silver screen.





## IN PARTNERSHIP WITH:

### THE PALLIATIVE CARE FUND



The Palliative Care Fund contributes to the development of palliative care in France, the improvement of the quality of care for those suffering from an illness and the support of their loved ones. Thanks to the expertise of its scientific committee, it selects or initiates innovative projects in palliative care in four action programs (general public and healthcare professionals information, research, development of non-medicinal approaches and digital services). It benefits from wide-ranging skills, which enable it to support projects in a personalized way.

www.fondssoinspalliatifs.fr

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"Taking talent to the top" is the Bettencourt Schueller Foundation's motto. For almost thirty years, it has been contributing to France's success and influence throughout the world. Its range of action covers three main realms: Life Sciences (research, scientific training, spread of scientific culture), arts (creative craftsmanship, choral singing, documentary) and the promotion of an inclusive society (personal autonomy, social bond, structuring the sector). In order to accomplish its mission, the Bettencourt Schueller Foundation awards prizes and funding to projects through grants, as well a very personalized support structure. The Bettencourt Schueller Foundation is the backer that enabled The Palliative Care Fund to become the film's partner.

www.fondationbs.org

And the involvement of 1,757 contributors on the crowdfunding platform kisskissbankbank:

The film received support from almost 2,000 people, who raised almost 100,000 euros, one of the highest amounts collected, after the documentary DEMAIN.

www.tinyurl.com/KKBBMistrals

## THE FILM CREW

Anne-Dauphine Julliand wanted to surround herself with a film crew whose sensitivity and discretion were essential to a smooth shoot. The directors of photography, Isabelle Razavet, Laurent Brunet, Katell Djian, Alexis Kavyrchine, Matthieu Fabbri, and sound engineer Quentin Romanet formed a tight-knit crew around the director, in order to follow the children and record their words.

Following the children's daily lives required continuous availability and talent from the five directors of photography. The film crew was light enough to put the children at ease and fit in unobtrusively with their families, healthcare services, schools, etc.



#### ISABELLE RAZAVET

After having obtained a degree from the Fémis, Isabelle was DP on many films and documentaries by director Solveig Anspach. She's also worked twice with Jean-Xavier de Lestrade, including on his Oscar-winning documentary *Murder On A Sunday Morning*, which won Best Documentary Film at the 2002 Academy Awards.

### LAURENT BRUNET

Laurent worked as director of photography on Sylvie Ohayon's *Papa Was Not A Rolling Stone*, Martin Provost's Seraphine (Best Cinematography César Award in 2009), Eric Guirado's *The Grocer's Son* and Florence Strauss's documentary film *Between Two Notes*.

## KATELL DJIAN

Katel was camera operator on Nicolas Philibert's **To Be And To Have**, Patrizio Guzman's **Nostalgia For The Light** and more recently Nicolas Philibert's **La Maison de la Radio**.

#### **ALEXIS KAVYRCHINE**

Alexis worked with Christian Rouaud on her film **Leadersheep** (César Award for Best Documentary in 2012), with Olivier Peyon on **How I Came To Hate Maths** (César Award for Best Documentary in 2014) and with Thomas Salvador on the critically-acclaimed **Vincent n'a pas d'écailles**.

#### MATTHIEU FABBRI

Matthieu worked on Thomas Clay's **Fanny Lye Deliver'd** (UK), Marine Place's **Souffler plus fort que la mer** and a great number of short films such as Jeanne Privat's **En face** and Sophie-Clémentine Dubois's **Le Pissenlit**.

## QUENTIN ROMANET

Quentin was sound engineer on such documentaries as Louise Traon's Les Gants blancs, Gurvan Hue's Trop loin, trop proche, José Manuel Fernandes's Wakasa and a number of short films, including Jonathan Desoindre's The Salt of the Earth, Chiara Malta and Sébastien Laudenbach's Les Yeux du renard and Martin Scali's Trois Chats.

## **CREDITS**

With **Ambre** 

> Camille Imad Charles **Tugdual**

Written and directed by

**Anne-Dauphine JULLIAND** Édouard de VÉSINNE Produced by

Original soundtrack

ROB

Music publisher Incognita Music

Hippocampus – Éditions des Abysses Frédéric BRUNEEL

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Géraldine OHANA

Production manager Post production coordinator Directors of Photography Martin du GUERNY Laurent CANOVA

Katell DJIAN Isabelle RAZAVET

Alexis KAVYRCHINE

Matthieu FABBRI

Laurent BRUNET

Color timer Frédéric SAVOIR Sound engineer **Quentin ROMANET** 

Sound mixer Steven GHOUTI

Editors Lilian CORBEILLE

Mathieu GOASGUEN

Valérie LINDON Music supervisor Produced by Incognita Films

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