

crystalfoot  
for ELA



Crystalfoot, an exceptional work created by Baccarat for ELA, European Leukodystrophy Association based on Zinedine Zidane's humanistic footprint.

# Contents

- Become a legend!
- ELA International and Crystalfoot
- ELA International's missions
- Leukodystrophies
- ELA's fight · Key dates
- Zinedine Zidane, the humanistic footprint
- Zinedine Zidane, a strong commitment
- Baccarat
- The Baccarat artisans
- Contacts

# Become a legend!

Zinedine Zidane wanted his footprint to symbolise his profound commitment to the fight against leukodystrophies, an extremely serious illness which can destroy a healthy child's brain in just a few months. With this powerful gesture, he has chosen a real message of hope: "We have to rise up against this illness, continue to fight it and hold onto hope even though it's hard! You are not alone. I'll always be hear for ELA".

With the prestigious Maison Baccarat, which has rallied its more than two centuries-old expertise of its most talented craftspeople, this original work elegantly created for ELA embodies the impetus given to the hard-fought struggle that drives the whole ELA family in its cause.

Today, it's important for me to recommend that you join the movement already linked with big names. With Crystalfoot, you have the opportunity to join and be part of the greatest team in the world, the one that always hits the targets for ELA.

*Discover the history of this legendary crystal foot!*

*Guy Alba,*

*President of ELA International*



*On June 12, 2018 Crystalfoot was launched in the presence of ELA families, donors, creators at the Baccarat in Paris.*

# Zidane's Crystalfoot, an exceptional product

*On 15 May 2002, at the Champions League Final in Glasgow, Zinedine Zidane scored a magical, defining, legendary goal. With this achievement, he sent a message to the world: daring, mastery of movement and team spirit can win victories. The important thing is to believe and be determined.*

*To beat leukodystrophies (neurodegenerative genetic diseases) to try the impossible, is a duty and a fight to be fought at every moment. The important thing is to unite and not lose hope.*

*Moved by this fight, Maison Baccarat took up the challenge and utilised its excellent craftsmanship to create a unique work to benefit ELA International: a crystal foot made from the footprint of Zinedine Zidane, emblematic ELA ambassador since 2000.*

*By reserving this exceptional object, you are making an immense gesture of solidarity and contributing to funding medical research on leukodystrophies and to ELA's international development. You are joining the greatest team in the world, the one that scores goals for ELA!*

## How to reserve the crystal foot

*A limited series numbered from 1 to 100, issued by Baccarat as orders are placed is offered in full to ELA.*

*You can reserve your Crystalfoot:*

- either online: <http://crystalfoot.eu/ela/reservez-crystalfoot/>
- or by contacting ELA International: Jean-Luc Corti Tel. +352 691 104 985 • [jl.corti@elainternational.eu](mailto:jl.corti@elainternational.eu)
- or by contacting ELA France: Delphine Pernot  
Tel.: +33 (0)3 83 30 98 10 • [delphine.pernot@ela-asso.com](mailto:delphine.pernot@ela-asso.com)

*Payment is a donation of €40,000 to ELA France.*

*The ELA association undertakes to issue a tax receipt corresponding to your donation in order for you to benefit from donation tax allowance in your country of taxation.*



# ELA International and Crystalfoot

## **Lending impetus**

*Moving is part of life! You could say it is life. This is why sport is a strong axis of mobilisation for ELA. Movement for life was the inspiration for "Wear Your Trainers" and beat disease. From the beginning, we understood that we had to find a small army of generous young people, and schools are full of them. Young people are spontaneously generous, you just have to give them the opportunity. All we had to do was suggest something they could do: get moving to support ill children, and they gave impetus to this initiative in a wonderful show of solidarity.*

## **Going even further**

*When I embarked on the ELA adventure, I had no idea how long it would take to defeat leukodystrophies. It was my main objective, I was trying to do it as quickly as possible, I didn't think that 26 years later it would still be imperative for me. This is proof that we need long-term support. Zinedine Zidane is one of these faithful supporters. Without him, we would not have the development and the influence we have. This influence serves the purpose of ELA: to be able to carry out concrete actions at the bedside of sick children, in support of their families and to develop research.*

*To take the research against these rare diseases even further, I was looking for a new, strong, powerful and ambitious idea. We have no choice, we must be ambitious when facing serious illnesses. This idea came to me naturally, it was right in front of me. We are lucky to have Zinedine Zidane as an ELA ambassador. And with this emblematic figure, it became obvious that we should harness the magic foot which enchanted millions of spectators thanks to its prowess on the pitch.*

## **Attracting attention**

*I told myself that we had to make this foot a symbol and turn it into an object of art to attract attention. This is how the idea of the crystal foot was born. To achieve this, we had to gather forces. The first of these are the sick children who endure their illnesses and have something to teach all of us about life. It's enough to watch them living without complaining, while their everyday lives are heavy and complicated, full of suffering. The parents who take care of them without weakening also show us courage that we can hardly imagine to keep fighting.*

## **Giving yourself**

*Zizou has proved to us, both in his loyalty and determination of his commitment, the strength of his attachment to ELA. We've all seen his excellence on the pitch, but what is less well-known is the human quality of this extraordinary man, who agreed to give us his footprint as a part of himself.*

*A footprint which in turn has led the remarkable people at Baccarat, the leaders and Best Workers of France, to give themselves in order to create this unique, iconic, authentic work.*

*A beautiful collaboration, an effective coordination, a great mastery of movement and shared values to achieve an object of excellence. This crystal foot is a wonderful example for ELA.*

*Guy Alba,  
President of ELA International*



# ELA International's missions

- *Funding medical research on leukodystrophies*
- *Informing and supporting affected families*
  - *Raising public awareness*
- *Developing its action at international level*

## Developing research, a priority action for ELA International

ELA supports research in the field of leukodystrophies. To date, more than **511 research projects have been funded for a total of more than € 43.5 million.**

ELA's aim is to help French and international researchers better understand the mechanisms of the disease and its natural history, particularly through the discovery of evaluation tools and biomarkers, and help clinicians to carry out clinical trials in order to combat leukodystrophies.

Since its inception, through the publication of a call for tenders, ELA has been inviting the international scientific community to submit research projects in the field of leukodystrophies: clinical trials; clinical trial preparation; preclinical studies specifically testing therapies; development of relevant animal or cellular models of human leukodystrophies; study of the mechanisms responsible for the disease in order to identify new therapeutic approaches; research on the prevention and repair of white matter lesions in humans or in specific animal models of leukodystrophies. ELA has organised three international scientific congresses bringing together leading specialists in leukodystrophies and myelin repair. These events allowed to take stock of the latest discoveries in the field and to promote exchanges and collaborations between researchers/clinicians.

In order to keep families informed, every year ELA organises a symposium dedicated to patients and their families. On this occasion, specialists in leukodystrophies convey inform families about progress in the field in a simple and understandable way, and answer their questions. This is a unique moment of exchange between researchers/clinicians and patients.

## Leukodystrophies

genetic diseases that attack the nervous system in sick people

***The nervous system is essentially a current that passes through a sheath.***



***For a patient suffering from leukodystrophy, it becomes increasingly difficult for the current to pass.***

*These rare genetic diseases destroy the myelin (nerve sheath) of the nervous system. When this sheath is damaged, the current cannot pass, and nerve messages are interrupted resulting in loss of mobility and balance, loss of vision and hearing, loss of speech and memory... Every week in Europe, 20 to 40 children are born suffering from these terrible pathologies.*

# ELA's fight

*In 1992, together with two families with children affected by the disease, Guy Alba founded ELA (European Leukodystrophies Association). Leukodystrophy is a severely crippling genetic disease that affects children around the world every day. In 2015, he became President of ELA International-GEIE, created to bring together patients and their families as far as possible at European level, and even beyond, and to advance research into the disease. Thanks to the efforts of all (sponsors, experts, families, teams, etc.) who have offered their support for more than 25 years, ELA is now at the dawn of the first treatments and must redouble efficiency. The challenge is daunting but together, thanks to the endless energy of ELA's parents, who are both attentive and concerned about the harm that threatens children, and with the faithful and precious support of its ambassadors, ELA can win its ultimate battle.*

## Key dates

### 1992

- **Establishment of ELA** - 1992 marks the birth of the association, but also the discovery of the gene responsible for adrenoleukodystrophy, a first ray of hope for families.

### 1994

- **“Wear Your Trainers and Beat Disease”** - For this first time, the association appeals to schools... The idea of a major citizen operation is launched and will meet a renewed national success every year.

### 1996

- **ELA Recognised as a Public-Interest Organisation** - After having existed for only four years, ELA is awarded Recognition of Public Interest, undeniable proof of the quality of its work.

### 2000

- **Zinedine Zidane, a strong commitment** - The champion with a big heart who became extremely touched by ELA's fight gets involved and propels the Association to the forefront.

### 2009

- **First leukodystrophy gene therapy trial** - A milestone year for ELA families who discover a promising medical advancement. Professor Patrick Aubourg and Dr Nathalie Cartier publish the results of an adrenoleukodystrophy gene therapy trial funded by ELA. An innovation that unveils encouraging prospects concerning the treatment of leukodystrophies but also other diseases.

### 2014

- **First international clinical trial** - ELA and Medday launch the MD 1003 trial to test the benefits of a molecule in the treatment of an adult form of leukodystrophy. This test is launched simultaneously in Germany, France and Spain.

### 2015

- **Creation of ELA International** - Based in Luxembourg, ELA International aims to unite the action of all ELA structures and to create others to achieve as quickly as possible the ultimate goal: to defeat leukodystrophies, while offering the maximum support to families in their everyday lives. Today, ELA is present in nine countries: Germany, Belgium, Spain, France, Italy, Luxembourg, Switzerland, Japan and also in the Indian Ocean

### 2016

- The **“Wear Your Trainers and Beat Disease”** campaign sees growing success: in schools, 500,000 pupils are taking part in the 23<sup>rd</sup> edition; in companies, 25,000 employees walked for ELA during the 6<sup>th</sup> operation. A new record! Employees had access to a smartphone app to count the number of steps they had taken and compare this with that of other participants.

### 2017

- The **“Wear Your Trainers”** and beat disease campaign opens to the general public - After schools and then businesses, it is now time for the general public to get involved in the fight against leukodystrophies. From 24 August to 7 October, the general public “Wear Your Trainers” operation was born. As part of a connected solidarity challenge, the general public was faced with a social challenge on social networks: “Wear Your Trainers Around Your Neck!” Users were able to register on the [metstesbaskets.org](http://metstesbaskets.org) website to travel as many kilometres as possible throughout the operation. These kilometres were then converted into donations to ELA.
- **Second ELA Symposium** - At the initiative of ELA International, eminent specialists from several disciplines and countries (including the USA, Italy, Spain, England, Germany, the Netherlands and France...) gathered in the presence of patient representatives to enrich their mutual approaches to leukodystrophies. ELA international brought together biologists, doctors, pharmacists, industrialists, and scientists who reflected together on new therapeutic approaches.

### 2018

- **Launch of the Leuconnect platform** - ELA signs a framework agreement with Almerys (health data host) for Leuconnect: an online platform that revolutionises access to clinical studies for patients and their families. The patient becomes a player in research by enrolling as part of a cohort and applying directly to clinical studies.





# Zinedine Zidane, the humanistic footprint

*I am lucky that I can do what I like, and I am ELA's ambassador... As soon as someone speaks about the ELA family, it moves me! You can see so many things in the eyes of those kids who can hardly move anymore. The look on those kids' faces... It stays with me forever.*

## **Standing up to this injustice**

*When I started supporting the ELA family, I said to myself: you're healthy and you can do something for others. We're on this earth to help others, too. They need support and even though I'm very busy, I'll do the few things that I can to the best of my ability. Whenever I could, I would be there. It is important that none of these people feel alone. To me, they never will be. These families who stand up to this hard-everyday life and to this injustice, they give me strength.*

## **Leaving your mark**

*Sharing is the goal of everyone working around this project. Just look at Baccarat and its famous crystal craftsmanship, creating something for the ELA family, that really appeals to me. Talking about the project, making sure it is listened to, heard, seen, that it has a strong impact, that's my goal. So, giving this footprint to make the crystal foot means leaving not a little bit of oneself, but a lot of oneself. And that's something that ELA will always have.*

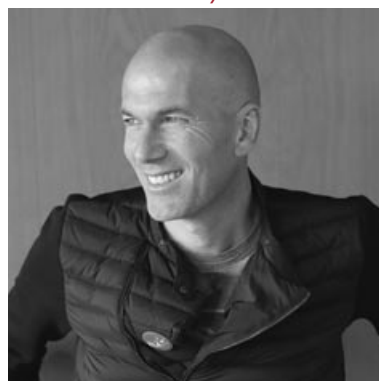
## **Sharing to win**

*Winning is not the most important thing. Winning is just the consequence. What counts is what you're going to give, the path you're going to take, what you'll go through with the team to be able to win. The most important thing is to believe. Being determined, really wanting something, giving all you've got...*

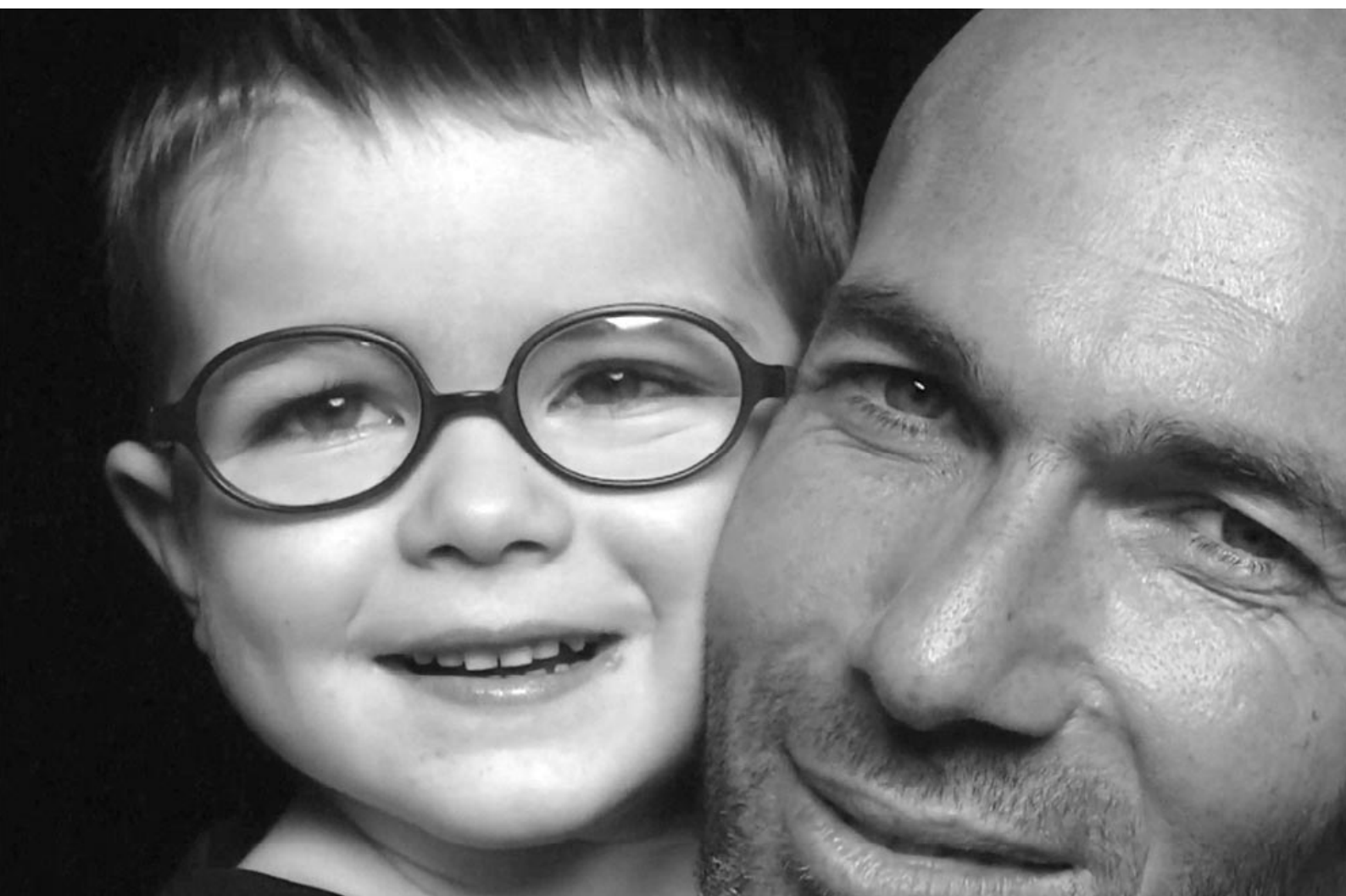
## **Keeping hope**

*For ELA, it's the same, we must stand up to this disease, fight it and try to eradicate it, to beat it. It's not easy, because everyday life is difficult, but we have to believe that one day this will come to an end. That is my message to all the families. Although it's tough you have to keep hope and I'll always be there for ELA.*

*Zinedine Zidane  
Honorary member of ELA*



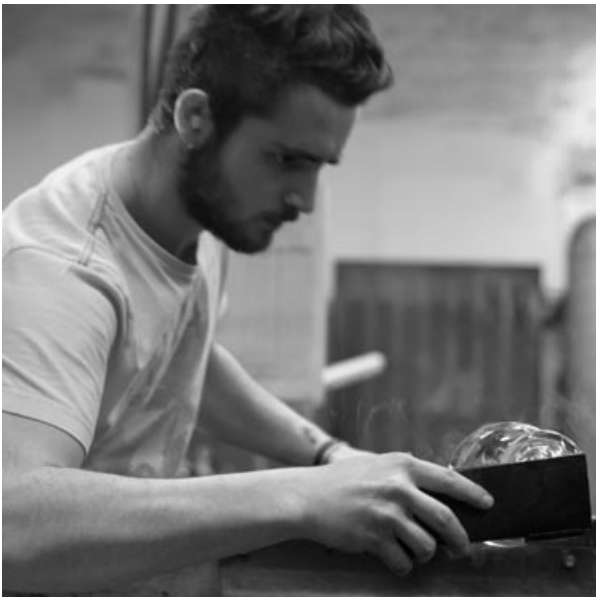
Zinedine Zidane,  
a strong commitment



**For 18 years, the world football champion has brought the fight of the European Leukodystrophy Association (ELA) to the forefront and regularly participates in numerous events organised for the association's benefit.**

- 2000 • Zinedine Zidane becomes an ELA ambassador through ELA honorary members Michel and Aldo Platini, and propels the association to the forefront.
- 2000 > 2004 • "Everyone in Trainers" operations: 2000 in Nancy / 2001 in Toulouse / 2002 in Lyon / 2003 in Paris / 2004 in Chambéry.
- 2002 • "ELA Zidane" broadcast on France 2, hosted by Michel Drucker.
- 2003 • "ELA Spring" broadcast on France 2, hosted by Michel Drucker.
- 2004 • "ELA Everyone" broadcast on France Télévisions, hosted by Florent Pagny, ELA honorary member, and Daniela Lumbroso.
- 2005 • New "Everyone ELA" broadcast on France Télévisions, hosted by Nagui.  
• "Celebrating Stadiums" operation in Rennes, in the company of many French celebrities.
- 2006 • Reading of the ELA Dictation written by François Morel.
- 2007 • "Stars excel for ELA" broadcast on TF1, hosted by Jean-Pierre Foucault and Benjamin Castaldi.
- 2008 • New "Stars excel for ELA" broadcast on TF1, hosted by Jean-Pierre Foucault and Benjamin Castaldi.  
• Launch of the "Save the Children" campaign to fund a therapeutic trial for metachromatic leukodystrophy.  
• Launch of the first "ELA Gift for Chance" campaign.
- 2008 > 2013 • Sponsor of the ELA Ambassador Award ceremony.
- 2009 • Launch of the second "ELA Gift for Chance" campaign at Stade Rennais in the presence of Salma Hayek and François-Henri Pinault, honorary member.  
• "Song of the Year" broadcast at the Palais des Sports in Paris, hosted by Florent Pagny and Sandrine Quétier, honorary ELA members.  
• Mont Blanc ascent with Christian Jeanpierre, ELA ambassador.
- 2010 • New "Stars excel for ELA" broadcast on TF1, hosted by Jean-Pierre Foucault, Benjamin Castaldi, Nikos Aliagas and Arthur.  
• Launch of an ELA postage stamp with Zinedine Zidane.  
• Charity football match at Stade Josy-Barthel, Luxembourg, on Europe Day and the 60th anniversary of the Schuman Declaration.
- 2010 > 2013 • ELA families' weekend at Disneyland Paris.
- 2012 • Call for donations as part of ELA's institutional campaign called "A Hero in Everyone." "Wear Your Trainers at Work" operation, Avenue Hoche in Paris, in the presence of Amel Bent and Grégoire, ELA ambassadors, and Sophie Thalmann, honorary member of the association.
- 2014 • "Wear Your Trainers at Work" cheque presentation ceremony at the Boston Consulting Group headquarters in Paris, in the presence of some thirty companies and a dozen ELA ambassadors.
- 2015 • Preface and promotion of "The art of ELA" comic book.  
• "Zinedine Zidane and Benjamin" clip.  
• Reading of the ELA Dictation by Zinedine Zidane.
- 2016 > 2017 • Sponsor of the ELA Ambassador Award ceremony.
- 2018 • 18 years of support and involvement.





# Baccarat

*Crowning jewel of Lorraine since its creation more than 250 years ago, Maison Baccarat is a symbol of excellence and art of living all over the world. The artisans' unique craftsmanship in this legendary manufacturing is the result of a long and delicate apprenticeship. A craftsmanship at the forefront of progress, passed down through the centuries by elite artisans and the reflection of an incomparable heritage. Baccarat counts among its teams a Chevalier des Lettres (Knight of Arts and Letters) and 15 Meilleurs Ouvriers de France (Best Workers of France), the greatest number of any French luxury brand.*

*With "Crystalfoot", Daniela Riccardi, Chief Executive Officer of Baccarat, and the brand's craftsmen used their talent to further ELA's cause. Requiring teamwork and precision, the manufacturing of this exceptional piece represents a major challenge: mould Zinedine Zidane's foot and carve it from crystal, a fascinating material that captures and reflects the light to make ELA shine throughout the world.*

*"When ELA asked us to participate in this project, Baccarat did not hesitate for one moment. Two legendary names, Zidane and Baccarat, join forces for the noblest cause: helping children with leukodystrophy.*

*The achievement of this magnificent "Crystalfoot" has created tremendous enthusiasm among the people of Baccarat.*

*From our Chevalier des Arts et des lettres, Nathalie Blaise, who physically took the imprint of Zinedine Zidane's magical foot, to our Meilleur Ouvrier de France, Raymond Regnault, who hand-carved the first piece, everyone at Baccarat has participated in this project with passion.*

*We will continue to stand alongside Zinedine Zidane and our friends at ELA to support their work and help them raise as many funds as possible. A hundred pieces will be made to order for all those who love Zinedine Zidane and wish to take action for ELA.*

*Some exceptional limited-edition pieces will go to an auction organised for the exclusive benefit of ELA.*

*Maison Baccarat is happy to be part of the greatest team in the world. Thank you."*

*Daniela Riccardi,  
Chief Executive Officer of Baccarat*





# The Baccarat artisans

## **A simple piece with a certain humility**

*In my mind there was no question of designing something frozen, it had to be something aerial, something moving. This movement brings another dimension to the object. I think that for ELA it means taking a new step forward.*

*This work has brought together the team's collective expertise to create a piece that will match the ELA ambassador. Like many, I am fascinated by Zinedine Zidane, I think that this creation is a little bit like his image: a simple piece, that favours a certain humility.*

**Nicolas Ledoux**  
Plastic Artist

## **A footprint - a strong sign**

*Zinedine Zidane represents a great deal for the people of my generation. Initially it was very important to take the footprint and draw the first model, the one that would serve throughout the creative process.*

*This footprint is that of an ELA ambassador, someone who is globally appreciated, who does a lot for this association. He lent himself very graciously, very simply, but he wanted us to take the mould of his left foot that scored the best goal of his career.*

*This made me think of the "Wear Your Trainers" to beat disease operation. Knowing that it is the foot of one of the most beloved French footballers represents a lot... The footprint is a strong sign. For Baccarat, each new piece is a challenge, it must be beautiful, and it is for ELA. This is important, so it really must be the best.*

*For me, being able to participate in my field and modelling for this cause, is a great way to make a positive difference.*

**Nathalie Blaise**  
Modeller, Chevalier des Arts et des Lettres

## **Like a birth**

*Zinedine Zidane is an icon, and to achieve something like this crystal foot (I think I've always dreamed a little of something like this), it is at the same time a pleasure and a pride.*

*Demoulding is a bit like a birth. You prepare beforehand, you have a waiting time related to the "cooking", and at the time of demoulding there is a feeling of apprehension: you release the piece of plaster, and as if by magic, you discover the shape you had prepared earlier which has now become crystal. The excellence of Baccarat lies in craftsmanship enhanced by sparkle. When you complete a piece, you get that shine - it's beautiful! When a piece is finished, we feel a kind of ecstasy.*

*For me, this foot is the expression of a desire to go forward, to kick off. For the association, I think that always going forward and not looking back too much is essential.*

**Raymond Regnault**  
Crystal Cutter, Meilleur Ouvrier de France

## **Great value**

*I am a Sèvres gold-gilder, my contribution is both accurate and valuable. I make the finishing touches for perfection, while considering the work that has already been done. We are very, very careful. A lot of thought has to go into my job, it is important to me, and when you love what you do, you do it to the best of your ability and with a lot of passion...*

*I have been really moved while working on this piece, I am happy to be here today with you and to participate in this project. It touches me, the association, and us here because what we are creating is of great value.*

**Angélique Unterner**  
Sèvres gold gilder



## Contacts



**ELA International**

25A Boulevard Royal

L-2449 Luxembourg

[www.elainternational.eu](http://www.elainternational.eu)

• Jean-Luc Corti: T. +352 691 104 985

[jl.corti@elainternational.eu](mailto:jl.corti@elainternational.eu)

**ELA France**

2, rue Mi-les-Vignes

CS 61024

54521 Laxou Cedex

[www.crystalfoot.eu](http://www.crystalfoot.eu)