

The bulletin of the Institute for Brain and Spinal Cord Disorders

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The Foundation of the Institute for Brain and Spinal Cord Disorders (ICM) is special by virtue of its multi-dimensional nature: grouping

together, at the same site, horizontal research in an international mission, which associates both public and private researchers, research and its clinical application, and also funds of both public and private origin.

The ICM Foundation's ambition - bringing together over 800 researchers, which will make it one of the leading global research centres - requires a substantial mobilization of funds.

The Foundation benefits, of course, from strong public support from the State, the Ile-de-France region and the City of Paris. Yet, it would not exist without the significant mobilization of private capital, over 12 million euros to date.

Significant as this amount is, it only represents a very small portion of what is required so that tomorrow the ICM Foundation will be able to operate to its full capacity. However, through research scholarships and the acquisition of a 3-Tesla MRI, the ICM mission, serving research, has already begun and is in need of your support.

Indeed, every year we have to raise this same sum of money.

The challenge for patients and their families and for public health in general is considerable. We are talking about a future priority for each and everyone of us.

By supporting ICM, you are supporting a cause which today affects millions of people in every country. Few families are in fact spared. And since people are living longer, the number of patients will inevitably increase.

Supporting ICM means helping to win this race against the clock!

Serge Weinberg, Treasurer of the ICM Foundation

→ ICM and Alzheimer Plan: the same challenge

The announcement of the Alzheimer Plan is both important and good news. Our leaders have shown their awareness of the magnitude of this public health problem and of the need to confront it globally: from both the medical (early detection, therapeutic care...) and medico-social sides (supporting helpers, creating adapted structures, etc.).

The patient must be central to the Alzheimer Plan: if the disease and its consequences are to be treated, the loss of patients' autonomy must be taken into account, together with their quality of life and also that of their families and supporters.

Cutting edge research is also vital to validate and optimise the measures already in place. This is the obvious way to develop and encourage hope that diseases can be prevented by early detection, and by treating the causes and factors that trigger them.

The research dimension of the Alzheimer Plan is three-fold, including basic research, clinical research and medico-social research.

ICM is a stakeholder in this research and its vocation is to be one of the main players in the Alzheimer Plan.

By definition, the ICM research programme is transversal, including all neurological brain and spinal cord disorders and, in particular, degenerative diseases, with Alzheimer's being a key component.

If the Alzheimer Plan and the ICM are indeed two distinct projects, their objectives certainly converge. The ICM will be one of the most powerful forces in the fight against Alzheimer's.

20 euros

This is the cost of a collectors' t-shirt from the prestigious designer Yves Saint Laurent, created by the no less prestigious, Stefano Pilati.

Designed for the 87th edition of the brand Marionaud's Prix d'Amérique, this collectors' t-shirt will be on sale from December 14, 2007 to February 29, 2008, on the site www.cheval-français.com, or by telephone at 0821 224 224, as well as at the Publicis Drugstore, and, of course, on January 28, 2008, the day of the Prix d'Amérique, at the Paris-Vincennes racecourse.



“Together, we are

Guy Alba, the founding President of the ELA Association



Last June, Gérard Saillant, ICM President, and Guy Alba, the ELA Association President, announced that they would be uniting their efforts in the fight against neurological diseases. Surprising? Not really: for 15 years, ELA has been fighting leucodystrophies.

Leucodystrophies: this word describes a set of genetic diseases which affect 160 babies born every year, or three per week, in France. Even if each case is different, the consequences are always very serious. Leucodystrophies are caused by imperfect growth of the myelin sheath, a white substance that acts as an insulator around nerve fibers. Once affected, myelin no longer transmits nervous messages correctly. Leucodystrophies manifest themselves in different ways depending on the location of the impaired myelin.

For example, if it is the brain area which processes images that is affected, this may finally result in partial or total blindness even though the eyes are perfectly intact.

Neurological manifestations surface at all ages and are often progressive:

- intellectual (understanding, memory, behaviour) function disorders
- sensation (vision, hearing) function disorders
- motor function disorders (walking)
- balance problems

In the absence of treatment, these manifestations increase more or less rapidly leading to total paralysis, blindness, deafness, inability to speak or to feed oneself normally.

Scientific discoveries on leukodystrophies are moving ahead slowly. Even if, in some cases, the faulty genes have been identified in the patients, the causes of around 30 % of leukodystrophies (called undetermined) are either not yet known or hardly known.

To date, there is no definite cure, nor any effective treatment to combat these diseases.

There are tests to scan for certain diseases, making it possible to see in blood, urine or from a skin biopsy the biochemical modifications characteristic of leukodystrophies. Nevertheless, the diagnosis very often is made too late and the disease has already developed.

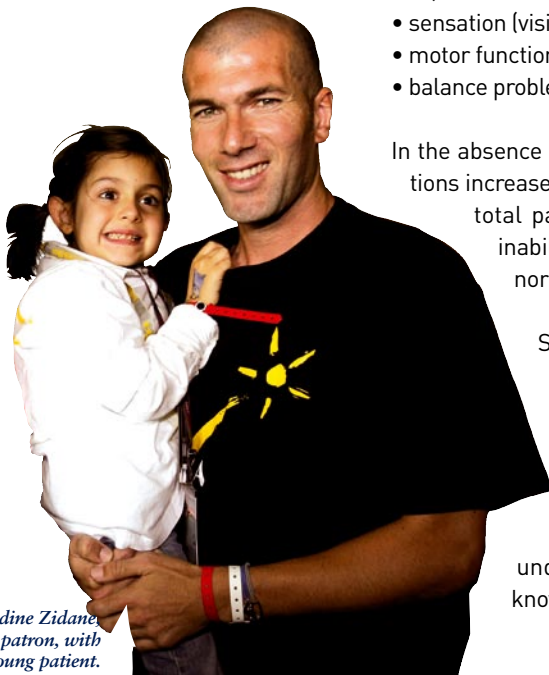
Today, few therapeutic possibilities exist. The bone marrow transplant is possible at an early stage of the disease for certain types of leukodystrophies. This possibility is rendered more difficult since compatible donors are rare.

Future research is set to move in different directions:

- isolation of the gene responsible for the disease: the first step towards a pharmacological solution for some leukodystrophies
- replacement of faulty genes: gene therapy
- repair of destroyed myelin
- identification of biochemical and genetic mechanisms responsible for non-identified leukodystrophies.

■ **Over and above the partnership set up on the occasion of the French Formula 1 Grand Prix in June 2007, what will be the relationship between the ELA Association and the ICM?**

The ICM research topics are in harmony with our action, and this is just the beginning of our joint venture. The aim of the ELA Association, created in 2005, is to fund research programmes. In the case of leukodystrophies, which, as you may know, are classified as orphan diseases, myelin is at the centre of everything. Problems that may be linked to myelin concern not only leukodystrophies, but also other pathologies, such as multiple sclerosis and even premature neurological dis-



Zinedine Zidane, ELA patron, with a young patient.

Professor Bertrand Fontaine's Research Team

The team of researchers led by Bertrand Fontaine, already at work on the Pitié-Salpêtrière site, is striving to comprehend the diseases linked to cell sensitivity dysfunction and to identify the genes causing multiple sclerosis, a very serious condition.

Like over fifty international research teams competing to join the ICM, Professor Fontaine's team will present its project to an international jury composed of well-known scientific public figures, who will make their decision official in 2008.

stronger”

eases. Once the ICM is ready to work on myelin, it is obvious that we will associate ourselves with them.

■ How would you participate?

The objective of our association has always been to bring leukodystrophies out of ano-

nymity and into the limelight and also to raise funds to advance research. ELA is an association of parents whose children suffer from these pathologies and who are fighting to combat the diseases. Let us first wait for the ICM building to become reality, and then once our Foundation has identified research programmes within ICM in need of funding, we will participate.

■ What does the forthcoming creation of this Institute represent for you?

A superb tool and a formidable concentration of expertise: another pointer to combat diseases. Together we are stronger! Yet, I also believe that there is a real ambition other than that, praiseworthy as it is, of witnessing the opening of an establishment of this type dedicated to research...

We share two main ideas with Professor Saillant....the first is that transversal research, likely to benefit many different diseases, must be given priority, whenever possible. This is the case, for example, of the ELA Association programme on myelin repair, which covers all diseases linked to this substance. The second is that research must allow us to improve the situation of the patients of today. To act so that in the future fewer people are victims is good, very good. But what we, as parents, want is research that can be applied to our children and to our sick friends as soon as possible. Our time factor is not the same and Professor Saillant has understood this.



photo credit: Stockbyte

→ AT A GLANCE

Michael Schumacher and Jean Todt will be on the big screen on January 30, 2008. These two active ICM members will act alongside Alain Delon, Clovis Cornillac, Gérard Depardieu and Zinédine Zidane! During the film preview, on January 13, 2008, a fund-raising operation for the benefit of ICM will be organised.

For the 3rd year in a row, the Paris running race "20 kilomètres de Paris" honoured ICM. Sportsmen and women as well as supporters could buy a bracelet in the colours of the Institute thus helping in the advancement of research.

Roland-Garros. This year the ICM joined the very select club of organisations associated with the Charity Day Benny Berthet at the Tennis 2007 French Open: a further opportunity to inform the public regarding the ICM project and to increase public awareness of ongoing brain research.

Professor Gérard Saillant and Jean Todt are patrons of the giant IDEC trimaran, which sports the ICM colours, and aboard which the skipper Francis Joyon will set off for a record solo trip around the world.

The newly revised ICM web site, launched at the beginning of November is more dynamic, making access easier for donors and presenting all the latest news and events of the Foundation. This new site includes sufficient space for a full presentation of the ICM project, with explanations and personal testimonies regarding the different diseases. www.icm-institute.org

Bertrand Delanoë hosted at the Paris City Hall the ICM partners' dinner on Monday October 22, 2007. On this occasion, Lindsay Owen-Jones announced that he was joining the ICM as a new founding member.

Luc Besson produced an advertising spot for the ICM that was aired in 157 Médiavision cinemas in September. It was also shown on World Alzheimer's Day.

Jean Reno, the ICM patron, is taking action to encourage people to make donations to the Institute. He is featured in the new press advertisement appealing for donations... coming soon!

Two exceptional champions for an exceptional cause

Saturday June 30, 2007, before the qualifications of the French Formula 1 Grand Prix, the ICM (Institute of Brain and Spinal Cord Disorders) and the ELA Association launched an appeal for donations and public mobilisation to fight neurological diseases.

On this occasion, in Magny-Cours, Michael Schumacher (seven times world Formula 1 champion and ICM founder member) and Zinedine Zidane (world football champion and emblematic ELA patron) met unexpectedly aboard a Ferrari driven a few times around the track by Michael Schumacher.

This was the first time that the two champions came together to increase public awareness of neurological and psychiatric disorders. Remember that one person in eight today is affected and that this figure is set to increase in the foreseeable future, due to the ageing of the population.



