SPECIAL FOCUS
ON AMYOTROPHIC LATERAL SCLEROSIS

SUMMARY

P. 2 News
The race of heroes

P. 4 Focus
Amyotrophic lateral sclerosis

P. 7 With You
A testimony: Parkinson disease

P. 8 With You
The advantage of recurrent support
FOR YOU & WITH YOU

Knowledge of the brain has increased without stopping these last thirty years. This field of investigation, which offers immense possibilities and is a real new frontier for science, fascinates but also raises questions. At a moment when the world is changing at an accelerating pace, it is essential to elucidate the functioning of the most extraordinary organ of the human body, both to advance our knowledge of its normal functioning and to understand its dysfunctions and imagine tomorrow’s treatments.

For 5 years now, the Brain and Spine Institute has been an innovative and ambitious pilot project that offers more than 600 researchers, clinicians, engineers, technicians and support personnel, an environment, unique in the world, for discovering in the shortest time possible new treatments against the diseases of the brain and spinal cord. All is in place so that the Institute can make the great discoveries that will enable us to prevent, cure and repair.

To celebrate this fifth anniversary with you, I have the pleasure of presenting the first edition of the Brain and Spine Institute Donors Journal, a bulletin dedicated to you, which will enable you to follow the activity of the Institute each trimester. The form and the contents have been elaborated for you, to enable you to discover with the researchers a timely subject, to express yourself and to receive answers to your questions.

I hope that this new format pleases you and will help reinforce our relations, so that we

Pr Gérard Saillant
President of the ICM

MAKE NEURONS TO FIGHT AGAINST ALZHEIMER DISEASE

A decrease in the mechanism of neurogenesis during aging is implicated in the development of neurodegenerative pathologies such as Alzheimer disease. Studies associating ICM researchers (Inserm / CNRS / Pierre and Marie Curie University), in collaboration with a team in the Cardiovascular research centre of Yale (USA), show the importance of the factor VEGF-C in the activation of neural stem cells and consequently the production of neurons. These results, published in Cell Reports, bring new hope for the development of therapies to compensate for cognitive decline in persons with Alzheimer disease.

ADVANCES IN THE NEUROSCIENCES QUESTION THE MORAL AND LEGAL RESPONSIBILITY OF RESEARCHERS

The philosopher John Harris made a noteworthy presentation in the neuroethics colloquium that took place in the ICM, in June 2014. His lecture was published in the well-known journal “The Cambridge Quarterly on Healthcare Ethics.” Find it on the site of the ICM / Communication / Conferences.

ON JUNE 21, EVERYBODY CAN RUN, SICK OR IN PERFECT HEALTH, YOUNG OR LESS YOUNG, A RUNNER OR A SEDENTARY PERSON, BLOND OR BRUNETTE

The race of heroes is accessible to just about everyone, athlete or not, because the participants have the choice of 3 formats, a 6 km walk, a 6 km race, a 6 km walk and a 10 km race. The Heroes register then create a fundraising page to collect at least 250 € of donations for the association of their choice. D-day is the occasion to share a convivial and festive moment. This year, the ICM will once again be represented by Anne-Claire Lenoir, our “super-hero” and her family. Find her testimony on the internet site of the Institute and, you too, come and participate in this unique and big-hearted sporting event.

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PARTNERS:
LET’S DRIVE FOR RESEARCH ON THE BRAIN AND SPINAL CORD

Four grand automobile events have been organized to support the ICM and help mobilize in the fight against the diseases of the nervous system.

Since its creation, the ICM has attracted many patrons and partners from the sporting and automobile world. September 12 and 13, 2015, the Lions Club Lyon-Doyen is organizing, for an entire weekend, a manifestation around luxury automobiles that is open to the public, with an exhibition and baptism in one of the dream cars. All of the profits will be donated to the ICM. Classic Days, Classic Festival and the Porsche Motor Club, gatherings of old and contemporary cars on famous automobile circuits, will also contribute their support this summer, adding pleasure to generosity for a day.

If you, too, wish to organise an event for the profit of the ICM, contact Agathe Gislot: agathe.gislot@icm-institute.org.

NEWS


• icm-institute.org/news
A start-up in the ICM is developing a treatment for the progressive form of multiple sclerosis.

• icm-institute.org/fr/the-conferences-of-the-icm
Find our researchers and a video of a lecture on Parkinson disease.

•icm-institute.org/fr/the-awareness-week-2015
Find the lectures of Brain Awareness Week 2015 and exclusive videos of the lectures of Eric Orsenna and Philippe Labro.

AGENDA

June 19, 2015, at 17:30*
Projection of the film “Une merveilleuse histoire du temps”—“The theory of Everything”—on ALS at the ICM

October 12, 2015*
Come and run the 20 km de Paris for the Institute

*Reservation obligatory at contact@icm-institute.org
Amyotrophic lateral sclerosis—ALS is characterized by a rapidly progressing paralysis (1 to 5 years after the appearance of the first symptoms) and a lack of effective treatments. Together with the core facilities and the clinicians of the Institute, the ICM team led by Séverine Boillée seeks to understand both how ALS is causes and how it evolves, in order to develop effective treatments for this fatal neurodegenerative disease.

ALS is still not well known in France and little studied because it is considered to be one of the rare diseases. However, the number of 8,000 persons affected by ALS in France hides another reality: the disease itself, for which effective treatments remain to be developed, causes a progressive, very disabling and fatal paralysis. It affects 5 persons in 100,000, generally when they are in their 50’s, and its frequency increases with age; this means, for each of us, a risk of 1 in 1,000 of having ALS by the age of 65.

In France, ALS is known as “Charcot’s disease”, the name of the neurologist of the Salpêtrière, Jean-Martin Charcot (1825-1893) who described it for the first time. Thus, the ICM, situated right where ALS was discovered and affiliated with teams having found the only active treatment for ALS, has chosen as its mission to develop strong translational research to find new effective treatments for this disease.

Séverine Boillée’s team at the ICM is searching for new causes of ALS and biochemical pathways implicated in the progression of the disease. ALS affects the neurons responsible for motricity, called motoneurons, which are situated in the brain and spinal cord. They are connected to muscles to which they send the signal to contract. In ALS, these signals are lost and the muscles atrophy leading to paralysis.

Motoneurons are the cells that die in ALS, but cells of the immune system (macrophages) in the spinal cord also contribute to the disease. A recent study of the team showed the implication of these immune cells in the disease, in particular of a pathway called “system xc-”, in ALS. They showed that system xc- was not expressed by the motoneurons themselves but by macrophages in the nervous system. They eliminated system xc- was not expressed by the immune cells, but also to target other factors expressed by the immune cells, might thus be able to slow the evolution of ALS.

This research relates to recent discoveries made by a European consortium to which one of the team members participated: mutations in a gene important for the immune system have just been implicated in ALS.

In order to find new therapeutic targets implicated in the interaction between the immune cells and the motoneurons, the team is developing experimental models of ALS, including human motoneurons obtained thanks to iPSc (pluripotent stem cell) technology, from skin biopsies taken from patients with ALS. This approach might lead to the development of new treatments that would slow the progression of the disease.

Identify new causes of ALS thanks to the zebra fish

Edor Kabashi’s team is specialized in the functional characterization of the genetics of ALS and has developed several models in the zebra fish to better understand the role of the major genes causing the disease. An essential advance in the work of this team was the development of the only vertebrate model reproducing the effects of the most important genetic cause of ALS in patients. These models have led to an understanding of the physiopathological mechanisms of the disease and helped the team identify several therapeutic targets for ALS and related diseases, including frontotemporal dementia.

THE TEAMS AT WORK

Thanks to the privileged location of the ICM at the heart of the Pitié-Salpêtrière Hospital, the clinicians (Drs. Meininger and Seilhean and Drs. Pradat and Salachas) work in close collaboration with the researchers. Séverine Boillée has also brought together researchers with complementary skills (Dr. Delphine Bohl, Dr. Christian Lobiger, Dr. Stéphanie Millecamps) to fight the disease more effectively.
The Brain and Spine Institute Donors Journal

6

THE MYSTERIOUS MOTONEURON

A

Presymptomatic

B

Symptomatic

The connexion between the motoneuron (red) and the muscle (green) is called the “neuromuscular junction.” One of the first consequences of the degeneration of motoneurons in ALS is disconnection of this junction so that the motoneuron can no longer transmit the order to make a movement. We use a model of ALS to study motoneuron degeneration.

A

Beginning of the disease: the neuromuscular junction (yellow) is still functional.

B

Disease in progress: the motoneuron and the muscle are no longer connected (the yellow has disappeared).

Photo: Christian S. Lobsiger

"I SUSPECTED FOR A WHILE THAT I HAD A HEALTH PROBLEM"

I no longer had a sense of smell, I neglected my right arm, became slow, less vigorous. Someone pointed out to me that I had become left handed! When the diagnosis of Parkinson disease was announced, I thought the sky had fallen on my head!

Parkinson, that’s a disease of old people. I thought I was much too young for that!

After a very difficult period of loneliness and depression, I decided to take myself in hand, and my friend Alain Marin, ICM donor, talked to me about this unique international research centre where all the neurodegenerative diseases are studied simultaneously and where the best researchers can be found. That gave me hope and the desire to persevere.

I was able to visit the laboratories and was very moved by contact with the researchers who were very motivated and generous with their time. They work for us, so we must support them as much as possible.

I now go regularly to the physical therapist, the orthoptician, and also do pneumatic relaxation in order to fight against stress, as well as acupuncture. I started taking piano lessons again, and when I’ve played for a few minutes I stop trembling...

Marie-Thérèse, age 61

Her complete testimony is on the site of the association Musique Passion Parkinson.

DONATION FORM

Please fill out and return this form with your contribution and your bank identification numbers - IBAN and BIC (RIB) to

ICM – Hôpital Pitié-Salpêtrière, 47 – 83 boulevard de l’Hôpital 75013 Paris

I support the ICM to overcome diseases of the nervous system

☐ Yes, I support the ICM to overcome diseases of the nervous system

☐ I am making a contribution of: ............................................ €

☐ By postal or bank check, to the order of the ICM

☐ By credit card (except American Express)

N° of your credit card ............................................

Expiration date ............................................ Date : ............................................

☐ I would like to receive free information on bequests and donations.

☐ You can make a donation online at: www.icm-institute.org

Sixty-six percent of your contribution to the ICM is deductible from your income tax (up to 20% of your taxable revenue), or 75% of your ISF (up to 50,000 euros).

Signature : __________________________ (obligatory)

Your coordinates

☐ Ms. ☐ Mr. ☐ Mr. and Ms.

First name : ............................................

Family name : ............................................

Address : ............................................

City : ............................................

Post office code : ............................................

Signature : __________________________

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City : ............................................

Post office code : ............................................

Email : ............................................

Telephone number : ............................................

In application of article 38 and the following articles of the law “Informatique et Libertés” of January 6, 1978, you can access, rectify and delete personal information concerning you. If you wish to exercise this right or don’t want your information to be transferred to third parties, it suffices to write to the ICM, Hôpital de la Salpêtrière, 47 – 83 boulevard de l’Hôpital 75013 Paris. You can also exercise through the special procedure for the protection of personal data of the National Commission for Data Processing.”
GIVE TIME FOR RESEARCH, ACCOMPANY OUR TEAMS OVER THE LONG TERM

With a recurrent donation by automatic withdrawal each month or trimester, you establish a long-lasting engagement with the ICM and assure that it receives resources regularly.

How do I do it?
It suffices to fill out the recurrent support form below and send it us with your bank details (BIC-IBAN).

What are the advantages?
For you: Donation by automatic withdrawal allows you, without bank charges, to distribute your support to the ICM over the entire year by giving a few euros each month or trimester, as you prefer. You will receive at the start of each year a single fiscal receipt for the totality of the donations made by automatic withdrawal the preceding year and you can stop the withdrawals whenever you want simply by contacting the donations department. It’s a flexible and practical system.

For us: The long term engagement of donors enables us to know our budget in advance: there is less risk of interrupting a project and more possibilities for planning. And especially, it gives even more hope to patients, because discoveries are the fruit of generosity, perseverance... and time.

THE DONATIONS DEPARTMENT AT YOUR DISPOSAL
Maylis de Gironde
01 57 27 40 22
contact@icm-institute.org

MY RECURRENT DONATION
Please fill out and return this form with your contribution and your bank identification details to ICM – Hôpital Pitié-Salpêtrière
47 – 83 boulevard de l'Hôpital 75013 Paris

SEPA AUTHORIZATION OF WITHDRAWAL
Type of payment: Recurrent – Unique authorization reference (1)
Beneficiary: INSTITUT DU CERVEAU ET DE LA MOELLE EPINIERE
IBAN: FR25 ZZZ 535582
You will receive the reference when the authorization is recorded

I authorize my bank to withdraw the sum indicated at the specified frequency. These withdrawals will be made on the 5th of each month or trimester following the date of the authorization.

MY COORDINATES
Family name: ____________________________ First name: ____________________________
Address: ________________________________________________________________
Post office code: __________ City: __________

THE COORDINATES OF MY ACCOUNT (BIC-IBAN)
International identification number of the account - IBAN
International code of your bank - BIC

Date (2): __/ __/ __2015
Place (2): Obligatory

Signature (2)

IMPORTANT
Don’t forget to include your bank details (BIC-IBAN)

By signing this form, you authorize the ICM to instruct your bank to debit your account according to the instructions of the ICM. You can be reimbursed by your bank according to the conditions that you have established together. A request for reimbursement must be presented within 6 months of the date of an authorized withdrawal. Your rights concerning the present authorization are explained in a document you can receive from your bank.

I WANT TO BECOME INVOLVED AND PARTICPATE IN CLINICAL TRIALS AT THE ICM AS A VOLUNTEER WITHOUT NEUROLOGICAL OR PSYCHIATRIC DISORDERS. IS THIS POSSIBLE?
Of course! To advance, research needs the support of everyone. You can contact Ms. Christiane Bourasseau, preferably by email:

secretaires.cic@psl.aphp.fr
or by phone 01 42 16 57 66
Monday and Thursday morning from 10:00 to 12:00

I’VE LOST MY FISCAL RECEIPT. HOW CAN I GET A DUPLICATE?
Contact the donations department and you will receive a duplicate by mail or email, as you prefer.

contact@icm-institute.org