

Similar and different



Dear Friends,

We have all been moved by the success of the London Paralympic Games, the sportsmen's zest for life and the spectators' enthusiasm. However, Elisabeth Zucman, a great lady known for her accomplishments regarding the disabled, still describes the relationship between the able-bodied and the disabled as follows: "when an able-bodied person meets someone vulnerable, due to fear and ignorance, they are likely to focus on the differences". (1)

In London, there was respect and openness: everyone was acknowledged as they were, be they sportsman or spectator, able-bodied or disabled .

Similar or different? The games, and its heroes, urge us to ask this question: what is similar? What is different? The willpower, the perseverance, the pleasure, the encounters, the person's plenitude? Perhaps the differences aren't where we believe them to be?

Sport is a way to reveal one's abilities. What sportsmen achieve is a daily fight: "life is a becoming for oneself". (2) I know personally many of these everyday heroes amongst our children. Similar and different, they eventually prevail over the ignorance and fear that surrounds them. Like Alexandre Jollien, they too can say: "I am determined to become what I am, with great patience." (3)

At La Fondation Motrice, the priorities for research in 2013 are clear: **pain** and **cognition** (how the signal is treated by the brain), its role in children's development and in troubles related with Cerebral Palsy.

Only your donations will make these programs effective.

Only your loyalty and your commitment allows us, along with researchers, to build something sustainable for the children..

You can also support us by putting together a team for the Heroes' Race within your workplace , with your friends, or by joining the one created by La Fondation Motrice. (4)

Thank you for your donations, thank you to our sponsor, our scientific council, to all the partner associations, and to volunteers and employees, for what they have accomplished this year in giving the researchers the means indispensable to their work.

I now invite you to confirm your support, in order for your donations to help us launch the 2013 research projects.

I wish you a wonderful Christmas and a happy new Year

Dr Alain Chatelin, President

Thanks to those who, after accompanying us for such a long time, have chosen another path: Louis Vallée, Maryvonne Lyazid and Pascal Jacob, to whom we owe a lot. Welcome to their successors on the Board of Directors: Pierre-Elie Carnot and Daniel Chastenet de Géry. Others will join us. Thanks also to Marie Roinet and welcome to Mélanie Bonnet, who is replacing her within the team.

- (1) Elisabeth Zucman. Personnes handicapées, personnes valides. Ensemble, semblables et différents. Erès 2012, p.200
- (2) Ibid, p.21, Tzvetan Todorov
- (3) A.Jolien, Petit traité de l'abandon. Seuil 2012, p.62
- (4) www.alvarum.com/fondationmotrice

Behind « sport and handicap »: pleasure, performance and encounter

2012 saw the amazing success of the Paralympics. Sprinter Sebastien Mобрé, title holder of the French and Worldwide championships, was competing on 100m and 200m in London. His fifth place left him unsatisfied: maintaining his inexhaustible desire to win!



Sebastien, you are one of today's best chair sprinters in France and even in Europe. Can you remind us of your career?

I'm suffering from Little Syndrome (1), which affects my lower limbs' motricity while leaving intact my upper limbs' coordination, which makes me able to move in a manual chair.

I've always liked sport. When I was a child, I was particularly fond of scuba diving. I loved this sensation of weightlessness, being in the water, it was very different of what I felt on dry land. In sixth grade, I got into a rehabilitation center that proposed swimming and I naturally chose this discipline. Thanks to my diving experience, I rapidly reached a good level and got hooked. That's when I discovered competition for the disabled.

How did you come to choose the athletics?

In my teens, while in training with my club, I felt badly in my room: my right hand was injured and I had to renounce high-level competition.

It took me a while to figure out what other sport I might like. One day, a colleague, who was training for a marathon, proposed me to participate. It was three weeks before the race, someone lent me a chair and I started preparing myself. Despite the lack of time, I managed to run the whole 42 kms and, more importantly, regained some of the sensations I once enjoyed. A member of the Sport's federation for the Handicapped saw me that day and convinced me to try the sprint. So I took my first license in athletics in 2004 and, six months later, I entered the French championship and won the title!

After that I felt a bit disappointed when I failed, not by far, to qualify for the Beijing Olympics. Therefore I started to train more intensely, in order to get my international career really started. In 2010, I broke the record on 100m, and in 2011, I got three medals in three races, including the gold on 100m, at the World championship.

What's your best memory, the Olympics or the world championships?

The Olympics are a privileged moment: all sports are represented, you meet more people there than during a normal competition, and the atmosphere is extraordinary. The opening parade is, by itself, a magical moment.

But my most personal memory remains the world championships of New Zealand, with my first "Marseillaise".

And then, what are your plans?

I think I'm gonna keep on competition until the Rio Olympics: the Olympic medal is the only one I haven't won yet. But then, I'll stop. I'm 31: one has to know when the moment comes to leave.

The most important thing for me is to have no regrets, and give the best I can, every time. Today my aim remains high-level competition, and I still want to win. After Rio, I will certainly be willing to invest myself as much, but it will be in my work and my personal life: I want to spend more time with the people who've been supporting me for all this time. I can't imagine life without objectives and desires, even if it is in other

domains. I will continue to dedicate myself to sport, maybe in another discipline. Maybe the triathlon, since I already know how to race and swim. That will certainly be very pleasurable.



My name is Agathe, I'm 14 and I've been practicing fencing for two years. I immediately found that awesome. It's very amusing to put the techniques into practice, in little assaults. It's a sport which requires some thinking, you got to be smarter than the other! I'm practicing every Wednesday, 45 mins with my teacher. Fencing allows me to let off some steam. I can relax and have fun, while giving the best of myself. Last year, I ended third at the Games for the Future, for the handicapped! I am always motivated to go to the club. Besides, it's a good way to make encounters.



Valerie, French living in London, was at the Paralympics. She tells us what she reminds of it.

What made you wish to attend the Paralympics?

At the beginning, I was motivated by the fact that I knew a little the world of handicap, since my nephew is motor-disabled. I think that for handicapped people, who handle huge stresses, the challenge is even stronger. First, I tried to watch team sports, since these are the sports I enjoy, but eventually, I attended mostly the events in which French people were competing: Paralympics or not, at the Games, you support your country!

What stroke you the most?

What stroke me was to see someone excel him/herself, as if sport allowed him/her to become stronger. I noticed that the ones who succeeded best were the same who didn't fight their handicap, but knew how to integrate it, and develop their potential elsewhere.

For instance, the Iranian team of volley-ball in chair, that won the competition, impressed me a lot: the players were way better than the others, they managed to be very mobile, and you could really forget that they were handicapped. On the other hand, their rivals were "handicapped by the handicap", the way able-bodied people unsure of themselves would be. Attending this game made me realize how important it is to control your body the way it is. It's only the beginning of what you do in life: in reality, there are no limits, and the human being is often his own enemy by lack of trust.

There's been a lot of talk about the "atmosphere" at the Paralympic Games, and the public's enthusiasm in London.

True, the atmosphere was great. There was lot of support from the public, many moving moments and friendships' stories. There was much respect for the sportsmen's achievements, rather than pity for their handicap.

If some people tend to mistake "handicapped" for "assisted", sport shows the handicapped in a situation of power and performance. That's the way it should be!



Marie-France Rietz, physiotherapist at Toulouse-Lautrec High School, in Vaucresson, an establishment that welcomes handicapped pupils: motor-disabled and able-bodied, explains how she supports involvement in sports, for young people with Cerebral Palsy.

The physiotherapist's role with the young sportsman depends on his pathology and the kind of sport he practices.

Regarding Cerebral Palsy, we are mostly useful after the effort, during the resting phase. Some sportsmen, especially the "standing" ones, often need stretching or massages. Most of the time, we intervene the day after the competition, to relieve of unusual contractions, or of pains related to some intense activity. Like for able-bodied people, we don't have to be there during the competition.

In some establishments, the physiotherapist has the possibility to help practicing certain disciplines like climbing, swimming, athletics, horse-riding, standing or in chair football. So he's able to use all his competencies to help the sportsman to be as efficient as possible, and advise him and lead him, as much for the event as for the resting.

In this context, we sometimes discover in the pupil certain capacities that we ignored, and that express themselves through sports. We get the same kind of "surprises" with the young people who prefer theatre, when they reveal onstage capacities of elocution and gestures more performing than in "real life".

(1) The Little Syndrome is a form of Cerebral Palsy that affects two limbs, usually both lower ones.

Two research projects supported by La Fondation Motrice, regarding physical activity.



The benefits of a regular physical activity on health and preventing ageing are now wildly recognized. But this doesn't concern able-bodied people only: practicing a physical activity, or a sport that isn't made impossible by the handicap, is considered a key element for the well-being. Interview with Nathalie Genès, physician and project manager at La Fondation Motrice.

What benefits can be expected from practicing a sport, for the handicapped?

As for able-bodied persons, practicing a physical activity puts in a better shape, by improving muscular strength, joint flexibility, gesture coordination and resistance to tiredness. It could also prevent complications related with a sedentary lifestyle and immobilization like joint stiffness, orthopaedic deformation, immobilization osteoporosis, or trophic troubles (troubles of tissues' nutrition).

But psychological benefits, and improvements in terms of autonomy, are as important. Sport allows to raise self-esteem, by forcing people to go out, to "show" themselves. The strength and self-confidence acquired that way can also be of help while facing daily life's obstacles, by allowing to develop a bigger functional autonomy, particularly movement capacities. Finally, we should talk of sport's social dimension. Sports facilitate social interactions with other participants (this is also true for able-bodied people), and even outside this sphere, social interactions can get better, thanks to an improved self-esteem.

Thus the handicapped who practice a sport are often better integrated at work, since they are better prepared, physically and psychologically.

What are the research paths on this theme?

The foundation supported two different projects.

The one led by **Pr Vincent Gautheron**, department head at St Etienne hospital, aimed at determining cardiovascular and muscular impact of tiredness after a long walk taken by teenagers and young adults with Cerebral Palsy (hemiplegic and diplegic). The results of this pilot study were that muscular fatigue was generating a significant decrease in muscular strength, an increase in pain, and an increase in the energetic cost necessary to maintain one's posture when walking. Some complementary studies are necessary to confirm these results. A better evaluation of walking capacities during this kind of exercises should allow an optimization of young people with Cerebral Palsy's reeducation.

The second project, led by **Marietta Van der Linden**, at the Queen Margaret University of Edinburg (Scotland), aimed at studying the feasibility of specific physical exercises' programs (bike, treadmill walking, muscles' reinforcing) for young people with a PC. This pilot study demonstrated their interest for the people having followed them, the beneficial effects on motricity and muscular strength, but also the need for individualized programs. It is also a first step before bigger scale's studies.

Support research by taking part in 2013's Heroes' Races.

Lille, June 2th / Lyon, June 9th / Paris June 16th / Bordeaux July 7th / Marseille October 6th

Registration from January : more information at mbonnet@lafondationmotrice.org



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