



Solann Dream Team

“The incommensurable need to run together”

It is not possible to describe the effect of such news on the life of a young couple: "your son has an irreversible brain injury that will cripple him all his life". The diagnosis falls like a cleaver without warning, abruptly, violently.

Each person affected by a tragedy, whatever it is, enters quickly in a process of resilience more or less long which allows over time to "go up the slope". For me, happy little Solann's father, the period of torpor following the announcement of the diagnosis was relatively short. Indeed, my hospital experience in Lourdes sanctuaire serving the sick and disabled, during my adolescence, unconsciously helped me to accept this situation, naturally helped me to project myself into the future, and I simply removed the urge to lower my head or resign myself without a fight. Moreover, my spiritual convictions and my faith in man often led me to worry about the other ... the others, before starting to feel sorry for myself.

Thus, the priority of the couple during the first years of Solann's life was focused on the organizational, medical, care and management aspects. The administrative way is laborious because the constitution of the files relating to the handicap is reserved for the graduates of a "master in patience". In addition, specialized childcare facilities for small children with multiple disabilities are not numerous and places are expensive. Thus, when the system of shared nanny was no longer possible, the small Solann was admitted at the age of 3 in a kindergarten adapted. Because Solann is prone to breathing difficulties, repeated infections, and epilepsy, pediatric emergency departments in Paris hospitals have occupied many of our nights, evenings and weekends. Weekly care was therefore focused on respiratory physiotherapy and motor skills. For several years, Solann followed weekly physiotherapy sessions with a specialist in cerebral palsy. The solicitation of his brain during the first years is essential to develop the still weak functional part of the brain.

Luckily, and this must be emphasized, France deploys a health system, which provides real help for technical and financial support, particularly in the case of disability in children. We are also fortunate to live in the Paris region, one of the best endowed regions for the management of the polyhandicape. The medical staff, the health professionals, the various specialists are all dedicated individuals and involved in the accompaniment of the difficulties encountered by children and their families. In hindsight, one of the important areas of improvement concerns coordination in the health care pathway. Indeed, the absence of coordinator between the speakers does not allow decompartmentalize the work of each specialist and develop a global approach in the care of the child.

Of course, the energy and time spent on disability management is only possible with the unfailing support of a network of friends and family. The most difficult the first years is not to sacrifice. Do not sacrifice the couple, friends, hobbies, work. Continue to live as normally as possible without becoming isolated or isolating yourself in a social and medical bubble around disability. In this logic, we decided not to give up our professional life but also not to wait to conceive a second child then a third a few years later.

To continue to live normally, that implied to continue the practice of the sport, in particular of the race with mates the w.e. in the parks and woods of western Paris. The idea then sprouted in the minds of some of us to challenge the fate and still participate in Solann activities that are not a



priori accessible. That's how Solann hit snow slopes in his first years on a sled. Then one day it was the revelation: to run with Solann! Nathaly Pendleton, Solann's aunt, living in the United States, sends me a message one day with the link to a short video of a dad running with his handicapped son since the 1970s (Dick and Rick Hoyt). Alone in front of my computer for most of the night, I remain frozen with emotion, upset and crying in front of the story of this family. I then understand an essential thing that still guides me today: facing Solann's handicap, everything is possible! With willpower, courage and love everything is possible ... So you have to run ... run ... run ... this incommensurable need to run together! Not just for the sporting feat, but to replicate and duplicate that intense emotion that can muster enough strength to change things.

At the age of 3, Solann, surrounded by a handful of friends (his dream team), took part in a first sporting event: a 10 km race for disabled sports associations. Our hastily flocked slogan on t-shirts was born: Are you walking? NO ! I run...



Then a half marathon, then two, then three. These first sporting years made it possible to apprehend the participation of disabled athletes in a race in competition: the solicitation of the race organizers, the registrations, the mobilization of the riders, the logistics, the design of the t-shirt to be visible and to pass the message, the team race consisting of a stroller on the road among the other riders, the arrival, the post-race with the riders and their families, the thanks. These first racing experiences were experienced as a holiday, great moments of solidarity in the effort. The reception of the organizers, the other participants, the shared pleasure generated a demand from the participants with new riders, friends of more and more friends to try the handisport experience around Solann. A large team was even trained to participate in a race "Joelette" organized at the party center where Solann is greeted, all his friends and friends with multiple disabilities. The joy and happiness shared with the children are out of proportion to all the volunteer activities we had done each of us on our side. What a beautiful smile and what a joy for Solann and the children to be at the heart of the action!

Thus, with the increasing increase of the participants of the dream team races and rich of the enthusiasm of the previous participations, we decided to give a frame to our actions and created in December 2010 the association of the same name so as to broaden our scope with appropriate means.

The association Solann Dream Team is a team of solidarity friends who "run" Solann and children with multiple disabilities with others ... like others. She works for:

*** Involving multi-handicapped children in sporting events :**

beyond the difficulty of the handicap, to make possible these beautiful moments of sharing and mutual help during the races in competitions in teams around the children and to give an additional sense to the sports performance of valid persons.



*** Bring a different perspective on disability :**

promote the acceptance of disability by the greatest number and make valid children aware of the difference by communicating with young people, especially during meetings with primary school children.

*** Support the care of the handicap :**

to help childcare facilities and families in difficulty in the management of disability for children through aid for the financing of specific materials or equipment.

For nearly 10 years, the association has been investing with its volunteer team members to give the best of themselves to the service of children with multiple disabilities.

Some significant figures symbolize his actions:

- 275 team members involved in the activities
- 120 races in competition
- 17,500 km cumulated traveled
- More than 40 children accompanied during the races
- More than 15 classes of schoolchildren aware of disability
- € 5,000 donations per year

The association Solann Dream Team develops this immeasurable need to run together around the cause of disability. Through the proposed actions, team members have the opportunity to share strong sporting moments with children with multiple disabilities, to act to bring a different perspective on disability by deploying the notion of living together and fund projects to improve everyday life. of these children.

Régis LEBOSSÉ

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