

Every year approximately 20,000 patients from around the world come to Barcelona for treatment. Our magazine decided to acquaint its readers with the world-renowned centers and international experts that have turned Barcelona into one of the most prestigious cities in the world for medical care. Over several issues our guide to the world of Catalan medicine is Olga Solovieva, General Representative of BMA, the association of Barcelona's top hospitals, and Director of Barcelona Medical Consulting, the company established in order to assist foreign patients and develop international relationships with institutions of other countries.

# JOSEP MARÍA RAMÍREZ HELPING TO START NEW LIVES



Josep María Ramírez is a legendary figure. Something like Russia's Leonid Roshal, but in Catalonia. A permanent director of **Guttmann Institute** for 25 years, he converted this hospital into a leading neurorehabilitation center known the world over. A person committed to society and the disabled. A tireless fighter. A charismatic leader. And the "BOSS", as he is called at Guttmann with respect, reverence and a little fear. Because when angry – he is fearsome.

OLGA SC

I often show Catalonian hospitals to official delegations from other countries, but I usually reserve Guttmann Institute until the end of the visit because of its great impact. Even the most reserved officials leave with tears in their eyes. It is a very special place because of the patients' stories, because of the stories about overcoming adversity that occur here. Can you first tell me how people end up at Guttmann? What is the statistical probability of becoming your patient?

- Guttmann Institute provides medical care for patients with acute injuries affecting the central nervous system, normally with paralysis of two or all four limbs. Many are victims of traffic accidents. Just 10 years ago this risk was two out of every 100,000 inhabitants per year, often young people. And now, fortunately, this number has fallen by almost 70 percent due to the implementation of severe measures and penalties and due to better spinal column protection in

new cars. However, a new trend has emerged in spinal cord injuries, with more elderly people with osteoporosis who break their spine in an accidental fall. Osteoporosis prevention and treatment will help keep this trend from growing in the future.

ACQUIRING ADVANCED
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Almost half of your patients are people with spinal cord injuries, and the other half have suffered stroke or brain injuries, haven't they?

- Yes, and brain injuries are caused, again, in car and particularly motorcycle accidents. It is more serious, because there are cognitive disorders and problems with speech, memory, comprehension and decision making in addition to reduced mobility. That is, you are no longer the same as you were before the accident. Well, I repeat that the number of traffic accidents has decreased in recent years, but instead we have many patients who have had ischemic and hemorrhagic strokes.

I know that you specialize in neurorehabilitation after strokes in patients under the age of 65. Can you explain why? An increasing number of young people suffer from ischemic strokes. Most stroke survivors are unable to work, with all the tragic consequences that implies not only for the patient and his or her family, but also the medical, social and economic impact this has on society.

- Yes, Olga, our stroke patients are primarily young people. Our therapeutic program is extremely intensive and persons 65 and over are unlikely to be able to keep up such a pace. It is especially effective for young patients after accidents or with genetic disorders, after strokes or with neurodegenerative diseases, or the consequences of tumors and their surgery...

When these accidents happen here in Catalonia, a series of steps is strictly followed. After a traffic accident or a stroke a patient is referred

to one of the tertiary hospitals equipped with the most advanced technology, where the patient receives the best care in surgery and intensive care units. But as soon as the patient is stable he is immediately sent to Guttmann Institute. For treatment to be more effective is it important to start a course of neurorehabilitation as soon as possible?

- It is of vital importance! As soon as the patient is stable, the doctors of the first hospital are obliged to send the patient to a specialized neurorehabilitation center like the Guttmann Institute, taking two conditions into consideration. The patient should have a stable cardio-respiratory system and at least a minimum level of consciousness, because neurorehabilitation in the full sense of the word is impossible if the patient is in a coma. The patient can be on a mechanical ventilator, but he should be stable. And neurorehabilitation should be started immediately after both conditions are met.





#### Is it related to brain plasticity?

- Exactly. When we talk about restoration of lost functions, we mean the process that the brain starts by itself! Our brain is plastic and in hostile conditions it tries to adapt to new circumstances. Our goal is to take advantage of this ability and to "guide" it in such a way that its adaptation can recover functionality. The sooner rehabilitation treatment begins, the better the chance of a positive outcome. Really remarkable progress can be made in the first three to four months after a trauma or a stroke. Later it becomes more complicated. So as soon as a patient is referred to us after an intensive care unit we start to guide the brain, in order to help it recuperate functions in a particular way.

If we don't, the brain starts the adaptation process by itself, searching for simplest and easiest way. Suppose one of your arms can't move. For our brain it is easier to "forget" about this arm and learn to make movements with the other arm. So when the brain has already established new connections and structures for making movements and has forgotten about one of the arms, it becomes much more difficult to "retrain" it. That is why we always insist that after the emergency surgery and ICU, on the seventh or eighth day after the accident, the patient should be here.

How do people react to what has happened to them? What occurs when patients and their families arrive at Guttmann?

- At first...when a person understands what has been lost, the patient goes through a period of "mourning". It is

important to work with a psychologist and the rest of the team during that time. The environment is also important; at Guttmann the patient is always surrounded by people who are in the same situation and who sometimes serve an example to follow. The work with the family is even more complicated. We must understand that the family, as a rule, has already spent several days near a critical care unit where their loved one hovered between life and death. The fact that he or she is alive is a great joy. However, after that, people know that we have good results here at Guttmann and they sometimes believe that we will work intensively to fit their loved one with a robotic device and teach him or her to walk.

Here goes the taught part of our work. We have to give the family a thorough explanation about the outlook and expectations we see in this case and what the reality is. Sometimes it doesn't coincide with the family's expectations. For spinal cord injuries, we can determine the real outlook more or less definitely after the analysis made in the first days of treatment. With brain injuries it is impossible make a prognosis, everything is case-by-case and it is difficult to predict what to expect in the following three months... this ambiguity is hard to handle.

And here is where it is extremely helpful for patients and their families to communicate a lot with each other. An individual starts to watch those who are in the same situation closely. Some of them already walk, others don't, some have learnt to speak, and others still have difficulty speaking even after

months of treatment. The family members start to exchange impressions and what they should expect and what kind of work they have ahead begins to sink in. This is precisely when they suffer an attack of "mourning". The patient and his family understand what has been lost and that it won't be easy to get it back. The psychologist works with the patient and his family...and then intensive work in supervised and controlled conditions begins.

-Guttmann Institute is a referrel neurorehabilitation center in Spain and its patients are provided with free care according to the public health system if certain requirements are fulfilled. But it is also visited by patients from all over the world. I have talked to some of your patients and asked them to talk about those features that make Guttmann Institute an international expert center. I was really impressed as they named, although in different order, the same THREE features... I'll tell you what they are later. Now I would like to know your opinion about why Guttmann Institute is special, what makes it possible for it to get such high results?

I would also mention three features, perhaps the same ones as my patients... First of all, this is the experience of a brilliant team of professionals including doctors, nurses, physiotherapists,

speech therapists, all of them...it is simple to understand. As we are a highly specialized center and admit a huge number of patients with certain pathologies, this creates the effect of a concentrated critical mass, an extremely important notion to become a leading center. Our specialists treat up to 4,500 patients with serious neurological

disorders per year and end up learning to do it very well. In medicine, a patient doesn't need to be operated on by a Nobel laureate, but by a surgeon who operates on 10 patients a day using advanced technology. Guttmann Institute is one of the few centers in the world with such a high concentration of patients with acute neurological disorders. This critical mass is the foundation of our specialists' skill and experience. The second feature is the special clinical model of specialized rehabilitation: tailored, intensive, integral, with the principals of evidence-based medicine, with the application of advanced technology.

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### Could you decipher each term?

- Tailored neurorehabilitation means that when a patient arrives to GI, he is assessed by a rehabilitation specialist, occupational therapist specialist, nurse, physiotherapist, psychologist, social worker and, in the case of brain injuries, a speech therapist. Of course, dozens of other specialists will become involved in the work with this patient, but this will be his/her team, which knows every small change, gathers every morning to discuss the dynamics and goals and has a close relationship with the patient. First, we define the concrete needs and establish the rehabilitation goals. Every patient is assessed with an established care pathway which he or she will normally follow for three to four months and which will be changed in view of the results.

Everything will be adapted to address the individual needs of the patient. If he can only move his pupil, he will be given a computer he can use to write with his eyes; if he needs to be retrained to swallow, he will be provided with neurofeedback. We have all specialties; we can handle it if someone with poliomyelitis and a hip dislocation needs have a gynecological exam. We try to adapt everything for every patient, ensuring all possible comfort. All the details in the hospital are arranged for this. It is very important, as people in this situation are particularly vulnerable and the hospital's adaptation to the needs of every patient gives them a sense of confidence.

### I remember that when I first came to Guttmann Institute some years ago I was impressed by the intensive "training", by its pace. Tell us, what do you mean by "intensive" therapy?

- I mean that from 9 am to 5 pm, with a break for lunch, we create specialized and individualized activities for the patient, like physiotherapy, cognitive rehabilitation, intelligent robotic techniques, virtual reality and brain stimulation with neuronavigation. Every patient has his/his own multidisciplinary program. It's a full day of work... but only by keeping this pace can we achieve maximum success. This "training" doesn't stop, even after the normal schedule. When a patient gets up in the morning the nurse will tell her, "Come on, try to dress yourself today". If she can't, the nurse will help and provide advice on how to do it herself, and have her work a little harder the next day. Indeed, it is important to remember that here at Guttmann Institute there are people who are in a similar situation, who support, advise and inspire each other, so when a new patient in a wheelchair comes into the café at 6 pm and clumsily tries to hold a cup of coffee, another more experienced patient will give him a piece of advice: "Mate, try to do it like this, it's much easier!" So these are three months of highly intensive activities morning to night!

## I know that all the patients appreciate precisely this opportunity to make friends with other people in a similar situation and to observe how other people overcome the same problems...

- Exactly. We are sometimes incapable of solving a problem, someone's attitude...but here in the hospital the patients and their families often become aware of how to handle this problem day-to-day by watching others. And thanks to examples of other people they learn to see their situation in a different light and enjoy a high quality of life in a different way, under other circumstances.

Guttmann Institute is a university hospital where specialists from all over the world study, where a lot of research is done and internationally patented innovative methods are designed. You work only with protocols, follow and register all the data of dynamics...as I understand it, it's no easy task to apply evidence-based medicine in neurorehabilitation because of the small quantity of indicators which allow the comparison of data in homogeneous groups.

- However, modern therapy should always apply the principles of evidence-based medicine. For example, when a patient can walk at least a little, he is sent to the computerized walkway with synchronized dynamic, electromyographic and kinematic analysis to diagnose functional disorders, to obtain an objective evaluation of his dynamics and set an individual program. Then we register the results in objective figures and graphs and



trace the dynamics. This is the only way we can be sure that we really do everything that we must. In general, registration, control, checking and comparison with the best centers are the principal tools of our work. So we register all the data from our patients' recovery dynamics, comparing the results in each case with the international scales like FIM and with other famous hospitals worldwide.

I know that this practice in particular lets us speak about the highest level of therapeutic effectiveness. Officially, you achieve approximately 95% of the rehabilitation goals set by the therapeutic team at the time of patient's admission. By the way, can you mention the latest advances in the field of neurorehabilitation in recent years?

- There are a lot of new things, like excellent medications, magnetic resonance navigators, interactive robotic techniques, systems of electrical stimulation combined in some cases with virtual reality, tele-neurorehabilitation, a lot of other methods. However, acquiring advanced technology is less important than applying it correctly and effectively. Here we return to the idea of the experience and skill of clinicians.

Now I would like to mention the third feature of Guttmann Institute. I have already spoken about our specialists' experience and professionalism, but one more thing is also important. People must have passion to work at a place like this. Our team boasts over 400 people with a high degree of selflessness who enjoy their job. When specialists come to this place, where human suffering per square meter is highly concentrated in spite of all our success, they quickly decide if they can't continue or, on the contrary, assimilate and dedicate themselves entirely to this work. Within months here at Guttmann Institute we know if a professional will stay with us forever. When a person does his or her job with joy and love, when he or she establishes a personal relationship of trust with those people he or she takes care of, the entire perspective changes drastically.



This is why I would now like to speak about the human aspects. We have discussed the recovery of functions, which is priceless for a patient, but there is another aspect. The new situation changes the patient's entire lifestyle and that of the family. I very much like your slogan "Helping to start new lives"... I know that these are more than just words.

- Thank you. We try to take care of all aspects of life of the patients affected by the disease and we try to do it in such a way that the patient can become as independent as possible in these aspects! Olga, our patients should be taught to sit or walk again, if possible, but they also should be taught to live again with a high level of independence and joy. They should be retaught to take care of themselves, to drive a car, to work with a computer. We should help with social adaptation, with the patient's sex life; we should work a lot with the families! We try to cover everything somehow. Also, we try to fight for the rights of disabled people; we have contributed much to

this struggle. But now, with the crisis, we have to recuperate some things. For example, financial support for the families of our patients has decreased. One should take into account that, apart from hospitalization, which is free for citizens of Catalonia, each family that has a member with a disability like this needs an extra 30,000 euros per year, and public institutions now give

only 6,000. So the family has to make an extraordinary effort and heroic self-sacrifice...society is obliged to help in such a situation and we continue to try convincing our authorities of this

Josep Maria, you have ruled Guttmann with an iron hand for so many years. I also know that you always have many new projects. You are about to open a new residence for patients with neurological disorders, you are a member of a dozen committees, you organize congresses and are invited to roundtable discussions. On top of all this, you almost maniacally control everything at Guttmann Institute. Your energy is the stuff of legends. In addition, as far as I know, you stay up-to-date with the changes in any of your patients. I have seen you stop in the corridor and start talking to people many times...

- Well, the statement that I am well informed of all the changes of each patient is a bit of a stretch. It is my team that is well informed...I am in charge of the institute's staff, and in order to do it well I shouldn't lose personal connections with patients and should get more insight on their expectations, disappointments and their impressions of our work. And the only way to do that is to listen to what they want to tell you, share their experience and emotions, support those whom you can support.

In this hospital people who find themselves in a wheelchair are learning how to bathe, dress, drive a car, go shopping and cook again. Once a week a bus comes to take the patients and an instructor to a supermarket because in this new situation they must learn to live a social life and to do all these things that were so easy to do before. They learn to use a computer including those entirely adapted to their pathology, for example, a computer controlled by a movement of a pupil or with an adapted joystick, they play basketball, shoot a bow, learn to dive in the hospital pool and later experience a real dive with an instructor on the Costa Brava, they go from the hospital to mountain ski, also adapted for every particular case...

- Yes, Olga, you have already mentioned that the hospital's slogan is "Helping to start new lives" because our true passion is not only to achieve better functional results but to make people who find themselves in a new situation learn to have a decent independent lifestyle and enjoy a better quality of life with its difficulties and limitations, but also with its joys, like self-fulfillment, friendship, a sex life, sports, etc.

#### How do people react when their stay at the Guttmann hospital comes to end?

- Sometimes there is the second period of mourning. People are psychologically comfortable here; they are sometimes reluctant to go "out into the real world". That is why even while patients are admitted we make them go to the city or go home for a weekend if they can, we work with social adaptation and have an adaptive sports program. After the patient's release we propose an outpatient aftercare service

IN MEDICINE, A PATIENT

DOESN'T NEED TO BE OPERATED

ON BY A NOBEL LAUREATE, BUT

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or tele-neurorehabilitation through a computer. Not only Catalans but also our foreign patients often come back just to visit us or to inspire the new patients. The most beautiful moment is when you meet your patient who tells you his problems at work or with his kids, who are going through a "teenage rebellion" period... these are now his problems and not those of not being

able to move like the majority of other people. When a patient has the wheelchair under his bottom, but not in his head... the rehabilitation is finished!

We are friends and colleagues, too, so I know you well as a director, but what do you feel are your strengths and weaknesses as a leader?

-Well, as for my weaknesses... I am, perhaps, not assertive enough. I sometimes lose my temper. And my strong point is my capacity for leading people, to be able to inspire them with an idea or my enthusiasm. In fact, there is no sense in going to work if you aren't enthusiastic about it.

I often hear you say that "Guttmann has given and is still giving me so much". You repeat it as some kind of mantra. So what does Guttmann give you?

A job helps us to serve people, society... any job can do that. But when, as in my case, you can be useful to somebody in a particularly vulnerable situation...feeling useful, feeling like you can enhance the quality of life of another person is a real privilege. What else could you want? Also, here at Guttmann Institute I have gotten to know absolutely fantastic people, some are my colleges and others are my patients. Guttmann Institute is also the best antidote to pessimism. Every day our patients and their families are examples of overcoming adversity and sometimes of real heroism. So when you see these cases of amazing endurance and integrity, you evaluate your problems in a different way and concentrate on those things that are really important, like being happy and sharing your happiness with others, especially those you love most.

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