Interview: Alberto Guglielmo â?? President, Carlo Besta Institute, Italy

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Alberto Gugliemo, President of the Carlo Besta Institute in Milan, shares the changing perception of neurological diseases and neurological science in Italy, the nature of the instituteâ??s collaboration with the industry and the importance of easing regulations surrounding the hire of scientists.

As president of Italyâ??s leading scientific institute for neurology, how would you say neurology in Italy has developed, and what place does it occupy in the countryâ??s scientific community?

In general, I would say that neurology in Italy is very strong. It has a long tradition, and many specialists covering the medical needs of patients as well as the scientific and research aspects of the subject. There is a big distinction between translational neuroscience, which covers treatment and medical applications, and basic neuroscience, which is very well represented in the country. These two systems are represented by two different scientific associations. Translational neuroscience is represented by the Italian society of Neurology, while the Association for Neuroscience represents basic neuroscience.

Contrary to many other public research centers in Lombardia, this institute concentrates on only one unique disciplinary field: neurological research. This specialization obviously allows us to conduct cutting-edge research in the field of neurological research, and therefore we concentrate our efforts on diseases and research topics that other multi-disciplinary centers cannot afford.

Basically, on the neurological side, we start where other research centers stop, and we only take in patients who require treatment for which other important hospitals are not specialized enough. In a nutshell, patients affected by really rare or complex neurological diseases are those we regularly treat.

As a result, our relationship with the pharmaceutical industry is split into two areas. First, there is that area focused on clinical trials, and the development of products and devices. The second is to use those products to better understand the scientific implications of how these act on the nervous system.

Has the institute always partnered with the industry, or has that only emerged more recently as a result of the crisis?

We are relatively young when it comes to collaboration for clinical trials and research with the industry, and we have only really exploited this over the last ten years. This has depended to a large extent on the scientific director leading the institute. In the past we have had a large interest for pathogenic mechanisms, genetics and neuropharmacology. This interest was mainly in the participation of patients at the institute in trials designed to better understand those aspects. Over the past ten years we have moved from ten to twenty trials active at a time, to currently having more than one hundred active trials.

The other three main areas which we cover are neuroncology, neuroimmunology, and cognitive disorders. Besides this another important aspect is that we are the only institute in Italy with a neuropediatrics division. As a result, we are becoming a reference point for neurodevelopmental disorders.

Can you name some of your pharmaceutical partners?

Yes, we are currently working with Novartis, Roche, Sanofi, Merck and Almirall.

What benefits does the institute gain from hosting clinical trials and collaborating with the industry?

First of all, it gives us improvement from therapies, funds for performing research, and finally, we become part of a scientific network for knowledge sharing, which can be very valuable indirectly.

We find that in a lot of countries we go to, companies are hesitant to invest in Neurology as it is very difficult, expensive and time-consuming to develop something truly ground-breaking, and bringing it to market is far from certain. Do you see companies taking a similar view in Italy?

I would say that they are interested in the large amounts of patients we are able to collect. They are optimistic, but the problem with big pharma is that their aims are very much oriented towards furthering their developmental programs. However, this is not necessarily positively respected in the clinical aspect, because things do not move very rapidly in this field. For example, we have recently finished a clinical trial in a rare disease, and it will take more than one year to gather the results, to see if the effects were positive or negative, after that we can start applying to the government for market approval. This is all very expensive and time-consuming, which makes companies hesitant to invest and once they do, very much result-oriented, sometimes to the detriment of the scientific aspect of drug development.

As you said, the development of new drugs is very expensive. How do you get the majority of your funding in order to finance your part of that development?

Funding here comes for the largest part from the private sector. This is one reason that this institute is held in high esteem by government institutions, as our ability to raise funding partly through private sources eases the burden on them. Additionally, it has benefits for us, as the road to public funding in Italy is very long, and difficult to navigate. Being entirely dependent on public funding would limit

us greatly, as it is often not even known what the amount of public funding will be for any given year, until the year after, and even then it takes longer still for that money to be received. If we were dependent on public funding, we would have to anticipate our budget for two years ahead based on what we thought the government would be giving us.

Finally, in Italy there is also this opportunity for citizens to allocate 0.05% of their taxes to a specific research center. So the Institute relies on three different sources of public founding; our annual research fund, funding for finished research, and finally the 0.05% from citizensâ?? taxes.

Neurological diseases typically still suffer from a certain level of social stigma, does that affect your research efforts, and your efforts to help raise awareness for neurological diseases?

It is indeed more difficult for an institute like Carlo Besta to promote its activities. People suffering from neurological disease are, as you suggested, maybe more reluctant to speak publicly about their disease than in the case of cancer for instance. You can see patients on television shows explaining they had a breast cancer and that they were cured, and this gives hope to patients who are still suffering and lowers the social barriers surrounding such illnesses. But it is very difficult for patients suffering from epilepsy for instance, and especially when it affects children, to say publicly that they are suffering of a neurological disease.

This difficulty to encourage patients to share their experiences also complicates our ability to raise awareness and improve public knowledge on neurological diseases, even for the most common of them. For instance, in the case of Alzheimerâ??s, a patientâ??s family is often not able to determine if the patient should still live at home or be placed in an adapted curative center. As a result, the family is more likely to make inaccurate decisions after diagnosis, but above all they are not able to detect any early symptom of Alzheimerâ??s or Parkinsonâ??s. This is particularly crucial, because even if we are not able to cure theses diseases yet, an early screening can allow us to limit the development of the disease.

Despite these difficulties, the institute has been able to fund and support some remarkable projects, such as the Besta Neurosim Center. That center was launched one year ago as one of the most advanced centers for neurological research in the world. What have been some of its achievements to date?

The most interesting achievement is the new ability to remove brain cancer without leaving permanent cognitive deficits. This means that we can now enter the brain, remove as much of the cancer as possible, and have patients then returning to their lives without neurological handicaps. That is a huge step forward. We are now able to treat patients who have been undergoing treatment for years, sometimes a decade, and, perhaps, not cure them, but at least we can give them back their lives.

Are projects like this helping neuroscience gain more prominence in the eyes of the government, as it helps make Italy a reference point for neuroscience?

Yes, as we continue to discover new methods of research, and investments such as the Besta Neurosim Center, neuroscience is indeed becoming more interesting to parties such as the government, as well as pharmaceutical companies.

To perform research like this, you need access to many scientists who are highly competent in their field and well educated and experienced. For the industry as well, access to excellent scientists is essential. How would you rate the pipeline of talent in Italy?

This can still be a challenge. Not because the talent is not there, it is, however the bureaucracy surrounding the hiring of staff can be prohibitive in this respect. We do have some advantage here due to our status as an institute, and it certainly varies region to region, but this process needs to be improved to allow easier hiring of young, competent scientists.

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