



# INTERNATIONAL MEDICAL REVIEW ON DOWN'S SYNDROME

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## EDITORIAL

### New perspectives

### Las nuevas perspectivas

Jesús Flórez<sup>a,b,c</sup>

<sup>a</sup> Head of Pharmacology Department

<sup>b</sup> President of the Ibero American Down21 Foundation (Fundación Iberoamericana Down21)

<sup>c</sup> Scientific Advisor for the Cantabria Down Syndrome Foundation (Fundación Síndrome de Down de Cantabria), Santander, Spain

Available online 4 February 2016

We live in a time of global revolution with respect to individuals with Down syndrome. The field of genetics forges onward, unstoppable; knowledge of the intricacies of biology is increasing exponentially thanks to the support that comes from the availability of animal models, of varying characteristics and value. Families and professionals increase their efforts to expand cognitive abilities, temperament individualities, levels of autonomy and quality of life. And they are succeeding, but it is the individuals with Down syndrome themselves who are working hard to break down barriers and demonstrate all of their tremendous potential. However, at the same time, society is implacably applying its technical advances to keep such individuals from being born, once their conception has been discovered. In our country and in others around us, 90% of the foetuses that are diagnosed early are being eliminated. This is a cruel paradox that is depriving society of the human values that the individuals with Down syndrome give us.

But this is not the time for complaining. Quite the opposite. The XVI International Down Conference, organised in Barcelona by the Catalan Down Syndrome Foundation (*Fundació Catalana Síndrome de Down*), incisively tackled fundamental aspects of the lives of people with Down syndrome. The goal there was clear: expanding the perspectives of individuals with Down syndrome and those of their families in an effective and, above all, fully human way. What do we expect for their adult lives, increasingly involved and full of resources? How do we reduce or avoid possibly conflictive situations? How can we take advantage of the guidelines psychotherapists and educational psychologists offer us, in the

light of their experience? What can we expect from possible new drugs? How can we prepare for and improve the future, including aging?

Drug application deserves special attention. Current animal model experimentation has opened the door to investigating potential new pharmaceutical agents that can mitigate or improve some of the alterations that research is revealing. This is good, but at the same time it paves the way for exaggerated optimism, for expectations that are at times not solidly based; caution is required in assessing and using such products. We are beginning to see that their use often deviates from the preventative regulations dictated by researchers and sponsors. That is why families and professionals need to have clear ideas as to the benefits supposedly to be gained. And nothing is better for this than to pose the correct questions in two crucial areas: behaviour and cognition. Because that is the only way we will know if administering the product is worth it.

Exactly what are these benefits? What do they really improve? Logically, our hopes have to be in line with the child's mental age. Observing greater "general activity" is not enough. This increase could be useful if the individual showed a previous predominance of inactivity or sluggishness during the day. But, this greater activity, what does it lead to? Is it activity well aimed at simple but clear objectives, or does the individual simply move more? Is he or she more attentive and does that attention last longer? Does the child understand and interpret better what we say to them? Does the child's language improve, in agreement with their mental age, in comprehensibility, syntax, vocabulary

and wording of sentences? Does he or she collaborate more and more skilfully at home in accordance with the responsibilities given? Remember events, tasks and what is heard and seen more? Show more interest in what we say, in schoolwork? Accept guidance better and obey the instructions given? Plan his or her tasks and activities better?

Before administering any drug, you therefore have to be very clear about the parameters to be assessed in real, specific terms. This "improvement in cognition" that you are supposed to accept must translate into substantial impact targeted at the daily life of the individual: of the specific person affected. Because the decisive question would be: Does he or she really feel happier now?

Of course, we have to remember that the potential improvement sought might not be immediate; it might take

time to manifest itself. At any rate, no product is valid unless accompanied by permanent educational initiatives, persistently applied. And these initiatives should never be abandoned due to false confidence that there are no limits to what the drug will accomplish. Likewise, it is also essential to remember that positive results may owe more to our individual action than to the virtues of the drug. And it's important to emphasise this, because we might be administering drugs unnecessarily.

### **Conflict of interests**

The author states that there is no conflict of interests to declare.