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EDITORIAL

Trisomy 21: an amazing journey towards the dignity of others

Trisomía 21: viaje extraordinario a la dignidad de los otros

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From ignorance stems fear, insecurity and distrust. Knowing what is happening to us, who we are and how our genetic makeup, whatever that may be, can condition our existence is a good weapon to fight with in a society—all too often *against* a society—that is still not mature enough to accept what makes us unique. Moreover, we are still not ready to embrace these differences into our so-called “normality”, and it is this shortcoming that compounds how fragile we are when nature sets us upon a different path right from our mother’s womb. This is and has been my feeling: profound ignorance as to the identity of the person I love and care about most in my life: my son. And with this ignorance, we embarked upon the road to finding out more, coming to acceptance, and realising that negative thoughts about our lives would only lead to irrationality and detach us from the wealth of a person’s true nature. It was thus that one night from the bottom of my heart came the poem *Trisomy 21*. It was dedicated to Marc and used by my sister Núria, an outstanding authority on ethics, law and medicine and Director of the Borja Institute of Bioethics, at the latest conferences organised by the Down Syndrome Catalan Foundation.

With the passing of time I have explained that poem to myself as a mother’s written promise to acknowledge and understand his reality, the promise to allow him to surprise us, and to consider the difficulties that society inevitably causes for people with Down syndrome and any other disability. Years later I have wondered how it was that on that night this poem came straight from my heart, genetically personalising the difference: “The extra chromosome / we shall call the placid chromosome...”. Marc has never been a placid child—he is restless, buoyant and demanding, the centre of all attention, watched and observed, forever being judged and evaluated. Those

enormous eyes that captivated me from the instant he opened them have incessantly and persistently had all eyes on them, determined to see any tiny sign of progress towards the normality that we subconsciously believe will make them happy. Those enormous eyes that must never have known freedom from all the staring, which for all its love subconsciously stripped him of his independence and maybe also part of his dignity. Knowing that we are independent and free, masters of our own deeds and words, is what gives us our dignity. I have often felt that driven by love, seeking to respond on his behalf to the threats around us, we were trampling on his dignity, and, inevitably, in doing so we were laying him bare. We lay him bare. We disarm him from arming himself.

I would be unable to write in this journal from any other perspective or position than that of mother. I know nothing: I feel that I know nothing beyond the precious, rich experience of having been blessed with my son Marc. I can add nothing to the knowledge contained in this prestigious journal beyond the challenge I face day after day of learning more about my son and having even greater respect for his dignity, which he builds alone through his own identity, struggling on so that those around him will not shortcircuit him forever. Other parents may think he is just like any other child, but time has shown me that the way we look upon these people strips them of their independence, when just like us they strive to be free and in peace. Will he ever know the freedom to which all humans aspire?

This is our struggle: making sure he can be free and independent, notwithstanding the fact this means training him up to achieve these goals. Therein lies the paradox. The price of his future freedom is incessantly pushing him as he grows, getting him used to normality so that he can live in a cruel, absurdly competitive and rational world,

stripping him of his sincerity, spontaneity and emotional creativity which stem from the healthiest intuition to love others and smile. I hope we can find the happy medium to avoid this dynamic becoming a permanent paradox and one which makes him unhappy.

I do not know of any parent of any child with Down syndrome who does not seek happiness above and beyond anything else for their offspring. However, I have met many a mother and father who rarely ask their children if they are happy and who subconsciously channel all their efforts into boosting their intellectual, sporting and artistic performance, racking up the medals for a brilliant future. By the time we realise that thwarted happiness and dreams are too a high a

price to pay for excellence, it is too late. At the end of the road, when the years have gone by and the rat race is behind us, our gaze turns inwards and we realise that the smiles we let slip by took with them our ability to look upon the landscape purely for the pleasure of contemplating and cherishing it, without asking for anything in return. Our goal should be to strive so that those who are born like Marc with the natural, extraordinary condition of building our happiness, of blessing us with it right from day one, are not deprived of the chance to bestow on us the dignity that we lack—the dignity that they can offer others, that underpins all else, that makes us human, and that allows us to share the most intimacy when the chips are down.