

El síndrome de Down en perspectiva 2016

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EN RESUMEN | Los progresos realizados en la atención, cuidados e investigación sobre el síndrome de Down han permitido avanzar considerablemente en la realidad vital de las personas. La visión optimista y esperanzadora que razonablemente nos captura, no debe ocultar los problemas que aún se plantean: la persistente visión negativa y excluyente que la sociedad continúa manteniendo; las diferencias en salud, habilidades, conducta, atención entre un individuo y otro; la problemática que plantea la irrupción de fármacos que pretenden mejorar las funciones cognitivas.

ABSTRACT | Significant advances have been made in the research, care and attention to individuals with Down syndrome. The optimistic outlook should not overlook some persistent difficulties: the negative and rejecting vision of society; the inter-individual variability in medical, cognitive and behavioral concerns; and the challenges imposed by the use of incoming drugs positively tested in preclinical research.

La convivencia durante casi 40 años con el mundo del síndrome de Down, tanto en el terreno familiar como en el del estudio y la investigación, me ha permitido ampliar la perspectiva con la que puedo ahora contemplar y analizar la discapacidad intelectual en general, y el síndrome de Down en particular, desde la vivencia humana como padre y la pasión científica como profesional inmerso en el mundo de la neurociencia.

FRAGILIDAD Y DIGNIDAD: DOS CARAS DE UNA MISMA MONEDA

La presencia del síndrome de Down en nuestro mundo es inseparable de la realidad biológica de la especie humana, que está marcada indefectiblemente por su fragilidad intrínseca. Fragilidad y dignidad conforman un todo; son dos caras de la misma moneda, dos cualidades tan íntimamente unidas que ninguna consecuencia derivada de la fragilidad humana resta un ápice a su dignidad. Abordamos, pues, el síndrome de Down no como una entidad abstracta, marcada por un promedio o porcentaje de debilidades y fortalezas, sino como una realidad inscrita en el marco concreto de una persona, con sus capacidades y sus limitaciones. Esa persona es hermana mía, por definición: es una realidad que se nutre de mi misma especie y es tributaria de los mismos derechos y deberes que yo tengo, ajustados a sus reales posibilidades.

La ciencia nos ilumina para conocer y comprender las consecuencias de una determinada fragilidad—positivas y negativas, tengámoslo muy presente—; en nuestro caso la que deriva de la triple presencia de material genético asociado al cromosoma 21. La ciencia nos aporta claves, cada vez más ajustadas, que nos sirven para profundizar en los inmensos arcanos de una biología que se nos presenta cada vez más compleja y, por tanto, más apasionante.

Pero conocer más sobre el síndrome de Down a veces escuece porque nos enfrenta ante una realidad abierta que, con frecuencia y por desgracia, se nos quiere ocultar y escamotear... “Hay que dar buena imagen”, nos dicen los profesionales del marketing. Todo es bonito, todo es de rosa, todo es sencillo. No pasa nada. “Sólo son más lentos”, se nos miente.

El Sa Ndrome De Down

Padhraic Smyth



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