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CONFERENCE REPORT: "IMPROVING THE OUTCOME FOR CHILDREN WITH DOWN'S SYNDROME"

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A conference, entitled "Improving the outcome for children with Down syndrome", was held at the Institute of Child Health in London on 1st June, 1998. At this conference, a number of speakers from the Warner clinic (based in the US) presented claims about various unorthodox therapies, including the use of a nutritional supplement (called HAP CAPS). In this article, two doctors (who are the parents of a child with Down syndrome) present a report of, and their reactions to, some of the presentations.

Introduction

We are the parents of a young child with Down syndrome and in common with many other parents we often find ourselves having to evaluate various interventions or treatments which may be beneficial.

Our purpose in attending this conference was to find out more about nutritional intervention for children with Down syndrome. We were aware of the fact that this is not recommended by the Down's Syndrome Association (for England and Wales). The conference was organised by The Down's Syndrome Research Foundation, (not part of the Down's Syndrome Association), the expressed aim of the foundation is to promote research into Down syndrome.

The conference was held in The Institute of Child Health in London, seemingly giving it medical authenticity that appealed to us as doctors. We find ourselves more sympathetic to a scientific approach to new therapies, requiring proper research methods before claims of effectiveness are made. However, we are primarily parents and if we felt that something useful was being denied we would be every bit as keen as the next parent to procure it even if this meant conflict with our medical colleagues.

The purpose of this article is to impart our own views of the day that has left a lasting impression on us.

The conference

The day started with a presentation by Professor Sue Buckley from the University of Portsmouth and The Down Syndrome Educational Trust, discussing cognitive aspects. She presented recent research data and its implications with particular reference to speech, language and reading. She summed up by stressing the need for properly evaluated research before interventions could be endorsed.

Then followed an interesting personal and anecdotal presentation by Mrs. Ramachandran, the mother of a girl with Down syndrome and a woman of admirable energy and altruism, who had set up a centre for people with Down syndrome in southern India, where she lives. She concluded by praising Dr. Jack Warner (see below) and stated that she had started giving her daughter nutritional supplements as directed by the Warner clinic. She seemed to be convinced of its benefits and said that she was recommending it to others attending her centre.

The next four speakers were from Warner House Center for the Study and Treatment of Trisomy Disorders. Dr. Jack Warner is the President of the centre that appears to offer a multidisciplinary treatment programme including nutritional intervention. His presentation was extraordinarily inaccurate, unscientific and insulting, and it soon became the subject of heated debate. Dr. Warner appeared to have little insight into the sorts of lives led by the majority of young people with

Down syndrome today (i.e. largely integrated within a family unit and participating in as many of society's activities as possible). He seemed to be stuck with the stereotypical view of the institutionalised person portrayed in some outdated medical textbooks, and thus attributed the attainments of the children attending his clinic to nutritional intervention rather than to natural development in a more stimulating environment.

There were many benefits claimed for Dr. Warner's therapy including improved physical appearance, physical growth, hair growth and ability to live an independent adult life, but he presented no data at all. He does not appear to have published any of his results despite the claims to have treated 4,200 individuals. Unbelievably, the only evidence he could come up with for the effect of the nutritional intervention was that when children stopped taking the treatment for reasons of family break up or natural disaster (these were the two examples he gave) their condition worsened. It was extra ordinary that he did not even acknowledge the fact that the major life event could have had something to do with the change in the child.

In response to this presentation there was a vocal representation from the members of the medical profession present, who were at pains to distance themselves from Dr. Warner. They felt it important to make parents aware of the glaring deficiencies in his work. There were a number of parents who had already invested time and money into obtaining nutritional supplements and they seemed convinced that they had seen improvement in their children as a result. There was a reluctance to accept that this improvement could have happened anyway. The discussion realistically got out of hand and as such only a few people were able to express their views. There appeared to be a sense of anger towards some of the medical profession; parents felt information regarding this therapy was not freely available and wanted to know why a trial had not been set up.

The other speakers from Warner House were interesting, particularly a behavioural optometrist but they did not add to the main thrust of the day.

The meeting ended with a presentation by Dr. Cornelius Ani who had reviewed the literature on nutritional intervention in Down syndrome. He gave a lucid account of the science behind nutritional intervention, then detailed the

published studies. These were hampered by small numbers and lack of randomisation and overall were inconclusive. He concluded that a large randomised trial of early nutritional supplementation in Down syndrome versus no nutritional intervention could be justified on scientific grounds but that there would be major logistic difficulties to be overcome before such a study could go ahead.

At the end of the meeting there was a consensus of opinion that more research is warranted. However there was an apparent gulf between those parents wishing to pursue every available therapy to help their child and the medical profession whose training teaches a considered scientific approach, which may be perceived as obstructive.

Conclusion

As parents we came away from the meeting with strong feelings that the evidence to date is insufficient for us to wish to pursue nutritional supplementation. Whilst supporting the concept of a randomised trial of early nutritional intervention in Down syndrome we wonder how many parents would be prepared to enter a trial where they had no say whether their child received nutritional supplementation or placebo? They would also have to accept that the results may not be arrived at in time to be of use to their own children.