

Professor Regan
President of the RGO
27 Sussex Place
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31.10.2016

Dear Professor Regan,

We would like the opportunity to meet with you to discuss how the Down's Syndrome Association (DSA) and Down's Syndrome Scotland (DSS), as the two national organisations, could work with the RCOG to ensure that health professionals who support women during the screening process, diagnosis and birth, receive the necessary training and information about Down's syndrome to enable them to deliver balanced information in a supportive manner. The availability of NIPT in the private sector and pilot NHS hospitals has increased the need for improvements to be made in the training of health professionals. This was recognised in The RCOG's Scientific Impact Paper NO.15 (March 2014) which discussed the consequences of the introduction of NIPT on existing services.

'Resources for the education and training of health professionals offering this testing and pre-test information and discussion will be required.'

Our two charities cover the United Kingdom, providing information, advice and training on all aspects of the condition to people with Down's syndrome, their families and professionals. We respect and support women making choices about antenatal tests and their outcomes, regardless of the decisions they make. We acknowledge that the offer of prenatal testing for Down's syndrome is a routine part of antenatal care. The DSA and DSS want to ensure that the prenatal testing process informs all potential parents and professionals of both the joys and the challenges of having a child with Down's syndrome. We believe that before and during testing, accessible and current information must be provided in an unbiased way by well trained professionals. Information should include the accuracy of the tests and associated risks of further tests, the life prospects of people with Down's syndrome, the possible impact on families and the support available in the community.

The Down's Syndrome Association already provides a training module which could be used and further developed - 'Tell it Right Start it Right'. Its key objective is to ensure health professionals have up to date, accurate information about living with Down's syndrome. This knowledge will assist them to support expectant women/families through the screening process and beyond by sharing the information in a non-directive manner. The training also aims to improve the way in which new parents are told that their baby has Down's syndrome.

Down's Syndrome Scotland provides a similar course in Scotland called 'Breaking the News'. Delegates attending this training hear about personal experiences from the parents of a child with Down's syndrome and/or a young person with Down's syndrome and find out what support is available. The DSA training is accredited by the Royal College of Midwives, but is attended by a number of other professionals, including consultant obstetricians, paediatricians, sonographers and geneticists. DSS is currently pursuing accreditation of 'Breaking the News'.

Through our work, we have built a body of evidence which strongly suggests that a significant number of prospective parents taking part in the screening programmes for Down's syndrome and receiving antenatal care continue to be provided with inadequate, biased information. The DSA conducted two surveys (2009 and repeated in 2014) to identify the antenatal and neonatal experiences of parents of a child with Down's syndrome. Both surveys revealed that women did not recall being provided with enough information about Down's syndrome during their pregnancy. Data from the 2014 survey identified that 67% of respondents reported not being provided with any information about Down's syndrome by their healthcare services prior to screening. Of those respondents who went on to receive a positive test result only 25% reported receiving any form of counselling.


The provision and delivery of information across Scotland, England and Wales appears to be inconsistent and whilst there are examples of good practice, delivery is dependent upon the professional standards, interpersonal skills and training of individual health professionals. Despite the quality of the written information about current tests being relatively good, women still report feeling confused. In far too many cases there is a culture of presumed consent, where women feel pressured into accepting diagnostic tests or, more worryingly, an assumption that a diagnosis of Down's syndrome would result in a choice of termination.

A Family's experience:

I would hate anyone to go through what we went through who didn't have access to the information and support available from yourselves. I think that it is vital that health professionals are aware of Down's syndrome and are able to present a true and balanced picture so that parents can make an informed decision on all of the available information. Not just the scary stuff! We received the diagnosis of Down's syndrome when I was 33 weeks pregnant. I was given that diagnosis over the phone. I was told that a specialist nurse would contact me and she did but she was unable to see me for a couple of weeks so I felt left on my own at that point and sought out my own information. The paediatrician then told us they suspected Down's syndrome. He made us feel as if it was our fault, we were asked why we did not have testing before and when I explained that they were unable to do the test because of the baby's position his reply was 'maybe you should of had it done again'. We were given lots of leaflets with facts and figures but no one to talk to who really understood.

We would value the opportunity to discuss with you further how the work of the DSA and DSS in this important area could be incorporated and further developed by the RCOG.

Yours sincerely



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