



Pregnancy and Friedreich's ataxia

Leaflet produced by Ataxia UK and the Friedreich's Ataxia Research Alliance

A study has been published in the US which studied pregnancy in women with FA. The study's findings are presented here along with some additional comments from the study authors.

The researchers in this study recruited 31 women with FA who had had one or more pregnancies and collected information from them about their medical history, history of pregnancy and delivery and feelings about pregnancy related to having FA.

Information about the participants

The average age of onset of FA for the women who took part in the study was about 24 years old and the average age during the first pregnancy was nearly 26 years. Some of the women who participated in the study did not have a diagnosis of FA at the time of their pregnancy; diagnosis came later for them. About two thirds of women were non-ambulatory (ie: not able to walk). 35% of women requested that their partners had a genetic test for FA prior to conception. This genetic testing number might seem low but some of the women in the study were pregnant in the late 1980's and early 1990's before genetic testing was available and others were not diagnosed with FA at the time of pregnancy.

Information about the pregnancy

All women received regular obstetric care, with 42% also being followed by a cardiologist. 6.2% of pregnancies were deemed high risk pregnancies, although in only one case was this attributed to the woman having FA. In this case, as the woman was in a wheelchair, her doctor felt she was at high risk of deep vein thrombosis. About two thirds of women said they experienced at least one complication but the majority felt these were not related to their FA. The most common complication was pre-term birth (the incidence of this being about the same as the general population).

Did the ataxia change during pregnancy?

Interestingly there were mixed results when women were asked this question. Eight women believed pregnancy improved their symptoms (mostly saying their coordination and balance improved); ten women felt their symptoms got worst (most saying fatigue increased, followed

by urinary urgency and then speech, balance and coordination); thirteen did not feel that pregnancy affected their FA.

Information on giving birth

Most births were via vaginal delivery with the caesarian rate (22%) being lower than the United States' national average. A very high proportion (87%) of babies were born at term and of appropriate weights with no health complications.

Women's' feelings relating to pregnancy

About half women who took part said they were concerned about their symptoms getting worse during their pregnancy and a slightly higher proportion were concerned about being able to look after their baby. Many women felt that it would be easier to look after their children at the early stages of having FA. The majority of women believed that their children benefited from having a mother with FA as it made them more caring and understanding individuals, able to see the 'bigger picture' in life.

Conclusions

The researchers conclude that this study suggests that women with FA can have successful pregnancies. However, because the study only included 31 women, the authors caution against applying the results to all FA women. Due to the nature of FA, the researchers advise that prior to conception and during pregnancy women be followed by a cardiologist. Additionally, pregnant FA women should have their blood glucose levels measured regularly (due to the predisposition of people with FA to develop diabetes). There were mixed feelings amongst the women as to whether the ataxia changed during pregnancy. The importance of a supportive doctor was emphasised due to the concerns likely to be experienced by women with FA about having children. The authors recommend genetic counselling for any woman with FA and her partner considering pregnancy. Carrier testing is recommended for partners so that an accurate risk of FA to offspring can be determined.

For more information on this study readers are directed to the full paper:

Reference: Friedman *et al.* Pregnancy with Friedreich's ataxia: a retrospective review of medical risks and psychosocial implications. *Am J Obstet Gynecol* 2010.

<http://medicine.journalfeeds.com/obgyn/am-j-obstet-gynecol/pregnancy-with-friedreich-ataxia-a-retrospective-review-of-medical-risks-and-psychosocial-implications/20100519/>

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