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PREGNANCY AND INTENSE SPORTS POSE RISKS FOR THOSE WITH CONNECTIVE TISSUE DISORDERS

London, 7 October 2023 – People with connective tissue disorders such as Marfan syndrome that can cause expansion of the aorta should be assessed carefully before they embark on pregnancy or high-intensity sporting activity.

This was a key message from this month's 2023 Marfan Information Day, organised by charity Marfan Trust, and featuring talks on the latest research and guidelines from leading experts on inherited connective tissue problems that affect about one in 3,000 people in the UK.

Dr Anne Child, medical director of Marfan Trust, told the online audience of medical practitioners, patients and family members that although there are still many instances of these inherited conditions remaining undiagnosed, "I do find that doctors are much more aware of Marfan syndrome that they used to be."

She said that treatment of Marfan and similar conditions centres on controlling blood pressure, to minimise strain on the heart and aorta. Patients should also keep their weight down, avoid smoking and "exercise regularly".

Dr Isma Rafiq, consultant cardiologist at the High-Risk Pregnancy Service at Royal Brompton and Harefield Hospital, advised that pre-conception counselling is essential for women with Marfan. "If there is significant dilatation of the aortic root, that is high-risk during pregnancy and childbirth," she said.

The risk, and therefore the delivery options, vary depending on the extent of aortic dilatation. For women with little enlargement of the aorta when assessed, the risks of pregnancy and childbirth should be low. For those with moderate to severe dilatation, Caesarean section may be the best course, Dr Rafiq said.

There can also be issues post-partum, and patient should be carefully monitored. Pears (personalised external aortic root support) procedure may prove to be promising in this group. The most important take home me message from today's talk is" ***Preconception Counselling is the key to safety leading to the best maternal and foetal outcomes".***

Dr Sabiha Gati, consultant cardiologist at Royal Brompton Hospital, discussed the implications of connective tissue disorders for people's exercise regimes and sporting activities. "There is an exercise paradox. Taking exercise contributes to strengthening the heart and improving health, but equally there is the question of what is the safe level of exercise for people with Marfan?"

"For people with aortopathy, exercise guidance needs to be individualised. There is no one size fits all." She said that certain sorts of exercise can raise blood pressure and put pressure on artery walls, leading to further expansion of the aorta, and the risk of 'dissection' (puncture).

Dr Gati said: “For people with Marfan but without any aortic dilatation, avoid high- and very high-intensity contact and power sports. There is a preference for endurance sports. For those with Marfan and moderate dilatation, only do skill sports or mixed and endurance sports at low intensity, less than 55% of maximum heart rate for your age.”

For those with severe dilatation, all sports may be unwise, unless the patient has an aortic repair, she added.

The full programme from the 7 October 2023 Marfan Information Day included talks on:

- Pregnancy in Marfan Syndrome from Dr Isma Rafiq, Consultant Cardiologist, HIgh Risk Pregnancy Service
- Contact and Scleral Lenses in Marfan Syndrome from Yetunde Obadeyi BSc (Hons) MCOptom MSc DipTp (IP) Glau Higher Cert
- Treatment of Descending Aortic Dissection from Professor Christoph Nienaber, Consultant Cardiologist, Royal Brompton Hospital
- Gastrointestinal Problems & Marfan Syndrome from Professor Qasim Aziz, Professor of Neurogastroenterology, Wingate Institute of Neurogastroenterology
- Transitioning from Paediatric to Adult Care from Victoria Hilton & Joanne Jessup
- Exercise & Marfan Syndrome from Dr Sabiha Gati, Consultant Cardiologist, Royal Brompton Hospital
- Research at the Marfan Trust from Dr Jose Aragon-Martin; Neonatal Marfan Syndrome from Elsa Harte; Psychosocial Impact of MFS on the Family from Laxmi Thileepan; and Gastrointestinal Issues in Marfan Syndrome from Simon Khatra
- Intensive Nursing Post Surgery from Joanne Jessup
- Ageing Well with Marfan Syndrome from Dr Anne Child MD FRCP

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NOTE FOR EDITORS

Marfan Syndrome is an inherited disorder of the body’s connective tissue that can lead to medical problems affecting the heart, eyes and skeleton, requiring treatment to prevent life-threatening complications. It affects men, women and children of any race or ethnic group. Over 18,000 people are affected by Marfan syndrome in the UK, and many of these are undiagnosed. It was identified in 1896 by French physician, Antoine Marfan.

There are a number of similar conditions, such as Loeys-Dietz Syndrome, that also affect the heart and skeleton and can lead to dilatation of the aorta, requiring surgery. Severity of symptoms varies greatly among people carrying the relevant genes, and so do implications for life expectancy.

For more information, see https://www.marfantrust.org/