

Dr Nitha Naqvi (BSC_(hons), MBBS_(hons), MSc, FRCPCH) Paediatric Cardiology Consultant and lead of the Paediatric Marfan service at the Royal Brompton Hospital

Dr Naqvi qualified from Guy's and St Thomas's Hospitals medical school, London and her training includes working at Guy's, Birmingham Children's and Great Ormond Street hospitals. She has been awarded the British Congenital Cardiac Association prize for research and Royal Society of Medicine prize for paediatrics. As an expert in echocardiography in children and frequently invited to lecture around the globe. She informed

us about the Marfan service at the Royal Brompton Hospital in London..

I can't remember ever not wanting to be a doctor. Both my parents are NHS doctors and inspired me from an early age. As a young child my parents were junior doctors and I lived in different hospital accommodations around UK until I was 8 years. This explains why I always feel at home in the hospital environment and hospital canteen food seems like the most delicious home cooked food to my palate. Every Christmas day as a special treat my father would take me to visit his wards at Wigan Royal Infirmary when we gave gifts to the nurses so I always associated going to hospital with happy times. As I grew older I realised that hospitals are also the most serious of places at times. I have always enjoyed being with children so paediatrics was always for me.

Training to be a paediatric cardiologist is a long journey, many exams along the way. After 5 years at medical school (6 if you do a Bsc as I did), there is 1 year house jobs, then paediatric training which is up to a further 5 years. Then you begin your 5 yrs training specifically in paediatric cardiology. Much to learn and surprisingly the time flies by and certainly I have never been bored at work. I met my husband, also a doctor, in an elevator in St Thomas's hospital. He had a very trendy square stethoscope and our first conversation was all about stethoscopes!

Paediatric cardiologists care for children from the fetus until 16 years of age. This includes those born with congenital heart disease (such as holes in the heart), those who develop heart problems later such as cardiomyopathy, heart rhythm problems and also children with aortopathy (disease of the aorta). Some of the patients require cardiac surgery or interventional (keyhole cardiac catheter procedures) as babies or later in childhood. People often say to me that my job must be "so upsetting" but the converse is true. Children are incredibly resilient, their bodies recover faster than adults and I am always overawed by how brave and positive children and their families are. Amazingly children virtually never moan about their health; they might scream and kick whilst having a blood test but then a few minutes later are playing happily. It is immensely rewarding seeing children who have been so sick, recovering and going on to do all the things their peers do, like winning races at sports day, playing with their computers, enjoying teenage dramas and becoming successful young adults with more life experience than many middle aged people. I feel lucky to share their parents' pride in their achievements.

My interest in Marfan syndrome also began when I was a young girl. My father also called Dr Naqvi (pictured Page 16), would occasionally tell me about a rare but important condition called Marfan syndrome.

Overview of the Royal Brompton & Harefield Hospitals Marfan Service

- Run by world experts Dr Lorna Swan (adult congenital heart disease cardiologist), Dr Anand Saggar (genetics consultant), and myself with the help of first class paediatric and adult cardiac surgeons.
- A full primary diagnostic service is offered with specialist molecular genetics diagnostic work provided by St George's Hospital.
- Follow up cardiac service provided integrated with cardiac surgeons giving a holistic approach.
- Care from newborn to old age by the same team with the benefits of not needing to transition to a different hospital and new team at 16 years of age.

- Adult Marfan clinics are held twice a month at the Harefield site (just outside London), and also twice a month at the Royal Brompton site in central London.
- Evening clinics provided at the Royal Brompton for adult patients.
- Once a month family clinic when parents and children can have appointments the same afternoon.
- Christie Fox is the paediatric specialist cardiac nurse attached to the children's Marfan service.
- We accept referrals from GPs, and specialist doctors. We are unable to accept selfreferrals.
- Specialist maternity service for pregnant ladies with Marfan syndrome led by Dr Lorna Swan.
- Ongoing research including being an AIMS trial centre.
- This is an aortopathy service (not an Ehlers Danlos service).
- Children predicted to become particularly tall are referred to paediatric endocrinology specialists for hormonal treatment if the family wish.

Thank you for giving me the opportunity to write in your magazine and I hope to meet many of you at your next annual meeting.





Cardiovascular Care Partnership



CCCP (UK) Conference July 2015 – Manchester Attended by our member Karin Staniforth on behalf of the Marfan Association UK

I attended the British Cardiovascular Society Annual Conference on Wednesday 10th July in Manchester. This was held at Manchester Central and involved a number of stands for charities, pharmaceutical companies and medical suppliers. There were talks going on throughout the day on a huge range of medical topics.

I attended one in the morning on "Challenges in the Management of Valve Disease" and in the afternoon "Gene Therapy – ready for clinical prime time?" The main point I understood is that there are many clever people working worldwide furthering medical knowledge which is very encouraging to us all. I rather struggled to understand much more than that!

I talked to a number of the charities attending and left leaflets about Marfan syndrome with the British Heart Foundation, Cardiac Risk in the Young and SADS UK (Sudden Arrhythmic Death Syndrome). Also leaflets were available on the tables in the refreshments areas.

The people attending were mainly medical and I spoke to a couple of young doctors who were aware of Marfan syndrome and had patients with the condition. They, and a number of charities remembered Diana Perryman and Geraldine Morley and the Marfan Association UK from last year. It was a privilege to attend on behalf of the Marfan Association UK.

Christmas Fund Raising Appeal

We do hope that you will be able to sell the enclosed Raffle Tickets for the cause. You may like to purchase some Christmas cards and gifts, including our popular pens, notepads, tool kits, poem books, etc from our Christmas Catalogue.