

Help line/Direct line: 020 8383 5363

QUEEN CHARLOTTE'S AND CHELSEA HOSPITAL
NATIONAL CENTRE SUPPORT GROUP

Dear

We are having our spring meeting on Saturday 2nd June 2007, at 14.00 hours in the Parent Information Room on the Ground Floor, at Queen Charlotte's & Chelsea Hospital, Du Cane Road, London W12 0HS.

This will be an informal meeting and an opportunity for new and old (diagnosed years ago) patients to come together, have a chat or catch up and share experiences and to support one another. It is especially a good one for girls/women who have recently found out or those who might not have had any or appropriate support before. The attendance is usually good so you will get the chance to meet many girls/women with mrkh. You do not have to be alone and you will be amongst friends.

Your parents, partners and friends are also welcome, as they too need the understanding and support. They will form their own discussion group but will be supported by Davina.

Then, everyone will get back together at the end before the meeting draw to a close so you will be able to exchange contact numbers and email addresses or even arrange future appointments with Davina, if you wish.

As usual, light refreshments will be provided.

So do come and join us if you can.

We look forward to seeing as many of you as possible.

Best wishes,

Julie Quek
Clinical Nurse Specialist
Gynaecology Outpatient Department
Queen Charlotte's & Chelsea Hospital
Du Cane Road
London W12 0HS

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PLEASE DETACH AND RETURN TO THE ABOVE ADDRESS
.....

Full Name.....

I will/will not be able to attend.

Parent	YES	NO
Partner	YES	NO

Please delete as applicable

NEWSLETTER, JUNE 2007

Dear All,

Firstly just to say how much we're looking forward to seeing those of you who are able to attend the forthcoming support group meeting. Feedback from previous meetings reflects what a supportive, open and friendly atmosphere you create when coming together and how valuable you find this time; in terms of being able to share your thoughts, feelings and experiences not only as they relate to MRKH, but to the rest of your lives in general.

Having been in my role as Psychologist here at Queen Charlotte's Gynaecology Clinic for just over a year now, this also seemed like a good opportunity to introduce myself to those of you I've not yet met and to let you know a little about some of the support I offer as part of the team's holistic approach to your care.

As the process of trying to come to terms with MRKH brings with it a range of feelings which may be very difficult and painful for you and those closest to you, it can be helpful to talk with someone who is not otherwise involved in your life and who is already familiar with the syndrome and some of the associated issues.

Along with the rest of the team, I'm very mindful that many of you have long and costly commutes to and from your appointments here and that this often involves you taking time out of work and academic schedules to be able to attend. Sessions can therefore be offered on a 'one off' or ad-hoc basis, following your out-patient consultations or during the time some of you may spend up on the ward.

It may be that initially, you'd prefer to just say 'hello' and get a sense of the support I might offer you in the future, at a time when you feel more ready to talk. Sometimes sessions are used primarily to focus on providing information and helping you to develop active coping strategies, for example, as a means of managing phases of shock, anxiety, sadness, anger and low mood.

Inevitably, over time, your focus and emotional needs vary, which is why like the rest of the team, I have an 'open-door' policy. This means that you are very welcome to contact me and arrange to come back and see me at any stage, regardless of how long ago you may have been diagnosed and what support you may have received in the past.

I've already worked with some of you, in the context of both short and longer-term therapy and have felt privileged to be able to share in this process. I look forward to seeing you again, perhaps in the next few weeks at the meeting or during your next visit to the clinic.

For those of you I've not yet met - please do feel free to come and say 'hello' at the meeting or to contact the service by telephone, if you would like to arrange to come and see me for a session. I am based here on Tuesdays and Thursdays.

With best wishes,

Davina Orchard
Chartered Counselling Psychologist

YOUR SAY

I never remember my 'condition' having a name. I was diagnosed 18yrs ago at the age of 14yrs and to say my life fell apart was an understatement. All I ever wanted was to have children and that had been taken out of my control. I had to have "my womb" removed and a couple of years later one of my ovary had to be removed too so by the age of 16, I was taking HRT.

Whilst my life fell apart in London, my sister who was 16years old, was having her baby up in Durham, having a concealed pregnancy. I don't know how I got through it but eventually I did. All that bothered me at this stage was the infertility issue. Why me? What had I done to deserve this? All these questions went through my mind hundreds and thousands of times but nobody could answer my questions. I decided very early on, that this was my 'problem' and I was going to manage it all by myself. During my stay in hospital, Sister Little was fantastic (with her magic wand) she got me through the dreaded dilators which I found really difficult. I also had a lot of help from staff nurse Anne Fisher with whom I still swap Christmas cards. I seemed to grow up very quickly and became obsessed with looking at magazines to see if anybody wrote about my problem. They never did.

Of course, I was also looking for a doctor to perform womb transplants but I never found anyone either. I felt so alone! At this point, everywhere I looked I just seemed to be surrounded by pregnant women (looking back now I realise that, it wasn't the case). I attended the support group a few times but as I was the youngest one there, I found them very difficult and was an emotional wreck throughout them so I stopped going and dealt with this 'problem' on my own.

I completed my GCSE'S and went on to do my NNEB Diploma. I always wanted to do work with children and I was not going to let this stop me. Although my mum was very supportive I closed her out and did not involve her. I know that she would have been a great support but I did not want to involve anyone.

At 18yrs, I went to work as a child representative in Spain and was there for 3yrs. I suppose looking back I was running away from my problem. I had to take my dilators with me which was a drag although I had them down to a fine art. I had the time of my life and didn't really think about my problem too much.

I returned home and met Tony my husband now of 8yrs. Now I had never really shared my problem with anyone let alone a man this was going to be hard. Tony comes from a traditional Catholic family in which children play a big part. He gave me lots of reassurance, listened to me and gave me lots of hugs. When the tears came flooding and believe me, there were many as I had bottled this thing up for so long.

After 6months of being together we were engaged and I had finally began to share my problem with someone else, although it came slowly which sometimes frustrated Tony as I also closed him out so many times.

I now look at life very differently. I remember feeling that I was not a woman as, I had never had a period and how I wanted to know what it felt like. I began to feel really cheated.

The next few years were by far the most difficult for me. I am surprised I did not scare Tony off really. I finally broke down at my GP's surgery and ended up on anti depressants for 6months, which also made me feel like a failure. We then had some counselling up in Manchester and on my last session I finally let Tony in the room which, was a big achievement for me, as I had never done this with anyone. He has kept me together throughout all the difficult times.

Now we had began to tell family and some friends but it became our 'problem' and not just mine anymore. At this time, lots of friends and some family seemed to be all getting pregnant and the line came "...we've got something to tell you". We knew what that meant and it was heartbreaking every time but again Tony supported us through it. We had already decided early in our relationship that we would follow the adoption route. At our wedding, we had a bidding prayer said about us, hoping to adopt a baby, we thought this would stop family and friends who didn't know from asking when we were going to start our family and it worked.

So we married in 1998 and started the adoption path soon after. We made it clear to our Social Worker early on that we were young and wanted a young baby although we were told that not many babies were up for adoption and that perhaps we should aim for the under 12months age range. At this stage, I was working within the Health Visiting Team and knew that not many babies came up for adoption although there were a few and we wanted one of those. So we agreed on the under 6mths but really under 4mths and we also stated that we would accept twins as I had always dreamt of having twins. We spent the next few couple of years waiting and then finally in March 2001, we had a call came from the Social Worker. She had these 8week old twins for adoption and asked if we would be interested. We were on top of the world. How I had always dreamt of having twins, you can imagine how we felt after some uncertainty over the following 7weeks of not knowing whether we were getting our babies or not and there was a lot of red tape.

We finally met them when they were 14wks old, our healthy son and daughter now known, as George and Isobel. Yes, dreams really do come true and boy had mine!!! Our lives is so fulfilled. We are happy, content and extremely busy and it has remained this way to this day. We have two perfect children who make our lives complete. Looking back, it has been a roller-coaster of a ride and I don't think I took the best option of trying to deal with it all myself. But then, who knows what is best at 14 although you think you do, don't you?

It is now good to know that my problem has a name. I know MRKH and I have it. Nobody really knows why I have it but I do and I am not alone and that's ok. I hope this has been helpful to some of you. Dreams really do come true...all you have to do, is to believe.