

## **The QCCH MRKH Support Group Meeting**

**Saturday 20<sup>th</sup> May 2006**

The meeting was well attended on Saturday, with the majority coming from all over the UK. Some people even travelled the day before whilst some had to start their journeys at the crack of dawn, just to be on time for the meeting. There were 50 people in all - 25 girls/patients and 25 partners/parents/family members and friends. Miss Rose (consultant), Davina Orchard (psychologist) and myself, Julie Quek, (clinical nurse specialist) were also there for support. The overall feedback was very good and positive and certainly, everyone enjoyed the day and found it helpful.

### **Summary of feedback from Patients and parents/partners/relatives**

All women who attended the support group meeting commented that they had found it to be a helpful and positive experience. In particular, group members said that they found that talking about and listening to others' experiences of MRKH, helped to normalise some of their thoughts and feelings – allowing them to feel that they 'are not alone' and that 'there are others in the same boat'.

Many women commented on how comfortable and 'safe' they felt talking in their small groups and that this enabled them to share their experiences openly and to feel supported. A few girls also said that this was the only place and opportunity for them to talk about their mrkh as they were not comfortable to talk about their feelings at home. They were concerned that they might upset their mothers when discussed at home...so they "put on a brave face and try to get on with their lives".

A number of women said that they found it helpful to hear about how other women cope with and make sense of their experience of MRKH and that it was valuable to listen to the perspectives of women of different ages and backgrounds. Some members also commented on what a relief it was to hear of others who had experienced a similar sense of frustration associated with living with the syndrome and others said how beneficial it was that they had been able to laugh with each other as they shared their stories.

### **Newsletters**

Some women felt that the newsletters were a great way of helping them to feel that they had not been 'forgotten' – that they were still held in mind between consultations and after they had finished treatment. Other comments related to how informative the letters were and how they have helped to develop patients and relatives understanding of MRKH. A major theme also related to the 'Your Say' section of the newsletter – with a number

of women saying how inspirational they found some of the stories and how closely they could identify with many of the accounts.

### **Julie's Direct Line**

All of those who had contacted Julie on her direct line had found her to be supportive, reassuring and helpful – one even referred to it as her 'life line'!

### **Website and chat-room**

Those who had accessed the website and chat room said that they had found it to be a valuable resource. Many women expressed an interest in joining the chat-room and hoped to make contact with other patients in the future.

### **General feedback on the support group for relatives/partners**

Again, all those who attended the relative support group meeting found it to be a positive and helpful experience. In particular, members commented on how informative and supportive it had been. Group members remarked on how valuable and comforting it was to be able to talk openly and hear the perspectives and experiences of other parents, partners and friends.

A few commented expressed the usefulness of having a support group specifically for partners, so that they can talk in more detail about their experiences and help dispel some of the remaining myths associated with MRKH.

**NB.** The link-chatroom for parents and partners/relatives is now available. If you wish to join, please email me, your name and your partner's or relative's (for security purposes); a username and a password of your choice to: [jquek@hhnt.nhs.uk](mailto:jquek@hhnt.nhs.uk)