

**MRKH SUPPORT GROUP MEETING**  
**17 MAY 2003**

I received nearly 50 replies back for this meeting but unfortunately, many could not attend as they already had other engagements like being on holidays, work, meetings, other personal social events and school/university examinations. A couple of patients telephoned on the day as they had problems and difficulties with their train journey and therefore had to cancel at the last minute.

Nevertheless, despite the group being a rather small one this time, everyone who attended found the meeting beneficial. There was a nice mix of girls – some who were recently or newly diagnosed and some who were seen and treated 15 – 21 years ago.

A few of the girls and their parents asked for the group to meet more often. We would like to hear what the rest of you feel so if you wish to have more meetings yearly, please drop me a line or email me with your thoughts and ideas.

Here are the feedback from the meeting:  
**FEEDBACK FROM GIRLS/PATIENTS**

- Very useful - 100% beneficial. Very happy I came today and met all those lovely girls and women
- Everyone was very understanding and we all had a chance to have our say. I no longer feel alone and feel that I can now speak more openly. The session has answered many questions on Adoption for me as well as keeping my up to date with current practice. I look forward to coming again and will keep in contact with other patients
- I found my first time very useful. It was emotional to hear other people's stories and how we all connected in the same way. I have swapped addresses with one of the girls and we will stay in touch and help each other through. I wish there could be more sessions in a year – I feel comfortable and glad to come again.
- I like the atmosphere – open and friendly. It's really useful to hear other girls' experiences and to meet other people with the same condition. Thank you.
- I'm glad I came today. I felt I have learnt a little and I feel a bit more positive. Although I didn't say a lot at the meeting, I listened hard and began to feel more comfortable. I hope to come again in the future.
- As always, a very good day. It was nice to see you all and good to talk about our very special problems.
- Helpful today particularly for the newer girls. The smaller group seemed to encourage those dealing with "stuff" to talk...It's a good idea to have a speaker for the autumn meeting, I'm still interested in other options for having kids. Thanks Julie and Gill.

## FEEDBACK FROM PARENTS/PARTNERS

- I found the meeting very beneficial and helpful. It was nice to sit down and talk to other partners, parents and other girls connected to the condition, MRKH.
- Excellent! Has been a great help to us and especially to our daughter. It's very important not to think that you are alone with this problem.
- Well done Queen Charlotte's! Keep up the good work.
- I found the meeting very helpful from the point of view of a mother and hearing other parents' feelings and fears.
- As a partner, I found the meeting extremely helpful. Finding out how other partners have helped their loved ones through the same situation. R and H were a great help as they are much further down the line and showed us that perhaps there is light at the end of the tunnel.

We would like to thank everyone for your comments and contributions. Of course, we can always have more meetings a year if that is what the majority of you want. We'll await the response from more of you.

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## WHAT'S NEW

Just to let everyone know, [our MRKH website is now live](#) so if you have not signed up yet, take a look at your very own website.

What to do next:

1. Send me a username and password of your choice which, may consist of letters or numbers (I do not give out any of these).
2. You will be added to our list of bona fide users for the secure section.
3. You will then need to download AIM (AOL Instant Messenger) free of charge unless you already subscribe to AOL. Just follow the instructions on how to do this.
4. Next, you will be requested to register a buddy name and password with them.
5. Once you have done so, you need to email your Buddy details to me so we can put you on our MRKH Buddy List for the chatroom.
6. Join in and start chatting to other girls with MRKH.

If you have any problems regarding the website, please do not hesitate to contact me either by phone, email or post.