

QUEEN CHARLOTTE'S & CHELSEA HOSPITAL
MRKH NEWSLETTER - November 2007

Hello everyone,

Hope you all had a good summer.

For those of you who were unable to attend our last two meetings, here's an update. Overall, these were very well attended especially the autumn meeting on IVF Surrogacy, where we had an attendance of 70 people.

I would like to take this opportunity to say a big THANK YOU on behalf of everyone, to Tracey, Rob and baby Jack, Gemma and her mother, Gill for their courage and selflessness in sharing their invaluable individual experiences with all of us.

Certainly, everyone who was there found it very helpful and beneficial and it gave them hope... it was also inspiring, so much so that three other couples started their IVF Surrogacy programmes soon after.

For others the support group meetings provided them with the opportunity to meet and talk to other girls/women with mrkh so that they no longer felt alone as they shared and listened to each other's stories. Here's what they said:

QCCH Patient Support Group
IVF Surrogacy Meeting - 18th November 2006

Evaluation

We had a very good attendance for this meeting - 70 people came from all over the UK. This was a very special meeting. It was presented by two of our very own.

Tracey and Rob very kindly shared their IVF Surrogacy experience with everyone and brought their wonderful success story, little Jack.

Gemma and her mother Gill, who was also her surrogate mother, very courageously talked about their experiences of their IVF Surrogacy attempts...

Feedback on Today's Meeting

Although the overall verbal feedback from all the attendees was very good, only 10% of the evaluation forms were completed or returned.

Nevertheless, the girls who completed their forms gave these comments.

- The meeting was very well organised, relaxed and informative
- Turnout was impressive and reassuring and a pleasant surprise for our first meeting; nice to see so many people there x2
- The content – first hand experiences was very beneficial to us
- We were very nervous but so glad that we came x2
- Really good meeting – so interesting and informative and just the right amount of information from those who took part x3
- It was great to hear the stories of people who had been through IVF Surrogacy – thank you for everything!
- It was my first time so it was helpful to know and see others with the same condition
- Today's meeting was very informative as well as an emotional roller-coaster
- It was my first time and after 36 years, it was very, very good and helpful to meet someone else with MRKH. I was delighted to meet Tracey, Rob and baby Jack...I was really pleased and hopeful that IVF Surrogacy had worked for someone with MRKH. I was diagnosed in 1987 in Ireland and got very little information so to find out all this information about mrkh girls having viable eggs and viable embryos was so amazing
- Thank you Julie for inviting me and for all your work on Saturday
- Fantastic to see and hear personal experiences

- Really great! The best one I have been to – good to hear people’s stories, very touching, emotional and encouraging and made me realise that I could have a child of my own and also breast-feed
- Today’s meeting was inspirational! Thank you!
- It was a meeting with emotion and heart and that made all the difference
- I cannot express how grateful I am for coming to such an amazing session – everyone was understanding and direct. I learned so much and got straight answers from people with experience
- Finally I am surrounded by people with heart and feeling, people who know and understand mrkh and are not ashamed of it
- After years of being alone, I now feel part of a wonderful group of women
- Thank you to both MRKH girls and surrogate mum for their honesty, openness and bravery...it made a difference to my life listening to their stories.
- The meeting was perfect for us this time, thank you.
- Tracey said one line which has made a difference to me, she said “you can have your own baby, you just can’t carry it”. That statement was never a reality until I met Tracey, Rob and baby Jack on Saturday, thank you!
- My wife always seem more positive about life after coming to this centre, thanks

Newsletters

- Simple and really nice to hear other people’s stories and experiences with MRKH because they make you feel less alone and make you realise that we have the capacity to love and be loved
- Good, always interesting to hear other people’s experiences x3
- Excellent, I love reading “Your Say” because it makes me feel that I am not alone x3
- Always interesting to read the newsletters and I appreciate the continuing contact with the hospital
- I love reading them as it is a way of catching up...I would like to contribute and will email you soon

Helpline

50% said that they did not or had not used it but the other 50% who did, found it very helpful.

Website

Most of them said that they had registered on the website and a couple said that they would like to join. Some girls/women said that they used it for research purposes and some went on it from time to time. No other comments were made.

Patient Contacts

No comments were received but 4 girls/women volunteered themselves as patient contacts so they have been added to our contact list.

MRKH Patient Support Group **Spring Meeting – 2nd June 2007**

Evaluation

50 people attended this meeting – 30 patients and 20 partners, relatives and friends. This was a mixture of girls/women who had attended our meetings before but for the majority, it was their first time.

The “girls” divided themselves into 4 smaller groups and they were supported by Julie (clinical nurse specialist) and Davina (psychologist) whilst the partners, relatives and friends had support from Miss Gillian Rose (consultant).

There were 66% completed evaluation forms.
These were their comments/feedback.

Feedback on Today's Meeting

- It was nice to meet people and be able to speak to other people x3
- It is not a subject that you can discuss with general mates and good to meet with people who understand x3
- It was helpful talking and listening to everyone's experiences and issues that other people had gone through x4
- I have been to one before about 5 years ago - it was still good to share thoughts and feelings
- It was helpful to hear other people's experiences especially about the dilator therapy and it made me feel less frightened about it
- Nice to be able to swap groups and hear more people's experiences
- It was really lovely to get together with other girls and women
- It was nice the way it was, informal so that everyone could feel safe to chat about their experiences, really good, just the informality of it and everyone was so open and brilliant x5
- It is good and I have been coming for the last two years
- I have attended a couple of meetings before but today was the first time that I felt comfortable talking about my experience
- Great, lovely to hear other people's experiences
- I felt like I was not on my own with this and that there are women with mrkh that I can talk to; It was my first time and the most helpful part was meeting other girls with the same condition and realising that I was not on my own x4
- Useful to be able to speak to other people with the same problem x2
- It was interesting although it was a shame that I did not get to meet everyone but it was good to stay in my group to develop a discussion
- Being able to meet other patients and to see that they looked normal and were normal; Seeing other people with the same condition; I am really glad that I came, I have never met or spoken to anyone with mrkh before x3
- Although it was very helpful as it was my first meeting, most of the girls focused mainly on their futures and having babies...no help to me because I am older and past the having babies age
- I enjoyed talking to fellow mrkh patients; just talking about it helps x2
- The support group meetings are always helpful, it is comforting to hear the experiences of others...it helps me appreciate how far I have come
- We thought today's meeting was very helpful and we had a lot of different questions answered and everyone was very friendly
- The opportunity to talk with other parents and to share the experience I have already developed of handling the issues associated with mrkh, to benchmark my own experience with that of others and the opportunity to clarify any medical facts
- Excellent. Talking to others, sharing their experiences was good and I now feel more able and confident in supporting my friend
- Meeting other people with the same condition has helped me to understand more about the condition in the role of a supporting partner
- My first time – it was helpful but due to the distance, maybe we need more time

Newsletters

- Really helpful reading about other peoples experiences
- Good and nice to read x3
- It shows that there is hope because good things can happen
- It is good to know how mrkh have affected other people's lives and how they are coping x2
- The newsletters are always interesting to read and I find especially good for partners/friends to help them to understand mrkh and what it means

- Informative but would be better if we receive them more often
- I really like them even though the stories make me cry but the last one gave me hope
- I found some stories quite upsetting, as dreams don't always come true
- Very useful way of keeping in touch
- Good to know what's going on with other girls like me, am thinking of putting a story in myself
- All the newsletters relate to me and they all share what I am feeling
- I have not read it but my daughter found it helpful
- The newsletters helped because my partner and I realised that we were not the only ones trying to cope with this abnormal condition
- I think they are great as they keep me updated and "Your Say" page is a nice read and helps me to sometimes feel that I am not alone x3
- I really like the newsletters because they help me to think more optimistically about my future

Helpline

More than 30% of the attendees said that they had used the helpline.

- Julie is very easy and helpful, she always replies x5
- Brilliant when I needed some help and advice
- I have but found it difficult to hear due to my partial hearing loss so emails would be better
- I find that it is essential and an important part of the service especially when I have a problem, as Julie is only a phone call away
- Julie was very helpful when I wanted to find when to tell my 10year old daughter about her mrkh
- I have contacted Julie for help and assistance and she has always given me help and support

Website

- Informative, I have not joined yet but would like to x9
- It would be helpful to have people's ages
- Not yet been on it – I think we were in denial and lack of time x2
- Yes, I got on it when I was feeling very low
- It's a good site and easy to access
- It had good information comprehensive material and also a secure area
- Have not really used the chatroom because I don't like chat-rooms
- After this meeting I will join the chatroom
- My daughter has joined –she is helping others but at the same time it is helping her too
- I have not joined yet but my daughter has
- Conflict of interest prevents me from joining
- I find it helpful to chat to people whom I can relate to especially if they feel the same as me

Patient Contacts

- I would like to be put in touch with someone who has gone through IVF Surrogacy by email
- I am happy to be patient contact x8
- I would like to be in contact with someone by email or the chatroom
- I have been talking to a patient contact and I found this very helpful
- My daughter might need to be put in contact with someone
- I am already a patient contact, would like to talk to someone and help them but not seen or spoken to anyone yet X3

- It is nice to have someone to talk to whom I can totally relate to as it makes me feel better about myself, more than friends can

Suggestions

- Presentations
- Sub-meetings nearer to home and help to set them up would be helpful
- Less discussion and more fun activities
- It might be helpful to start by giving some information about mrkh for those of us who do not understand or for whom it was our first time (friend)
- I think that it is a good idea the way it is

“YOUR SAY”?

Unfortunately, I did not receive any stories for “Your Say” this time, despite my several reminders and encouragement. This is indeed rather disappointing, since the feedback on the stories had always been very good and positive.

So come on girls, this is your say, your story...it can be on anything, some happy or funny stories or events or celebrations that you would like to share with everyone, perhaps your wedding or holiday.

It's up to you, ONLY YOU can tell your story and keep this section alive and interesting...

GROUP THERAPY

Many of you will know Jacoline Heller (our previous psychologist) and some of you also participated in her group therapy study. Her paper has been published and was also recently accepted at the URL below. For anyone who is interested, please click here:

<http://humrep.oxfordjournals.org/cgi/content/abstract/dem167?ijkey=anfzMWDXKS4Gz&keytype=ref>

As her findings proved that group therapy had positive psychological outcomes on girls/women with mrkh, we are offering you the opportunity once again to take part in our future group therapy. If you are interested, please register today and leave your preferred contact telephone number or address and Davina will contact you with the details nearer the time.

Thank you.

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