

SEX & CONCEPTION ISSUE

Living with HIV and making decisions about whether or how to have children brings up many different issues and feelings for people. From sperm-washing to fostering, to doing it naturally or not at all. Would you like to have children but are worried about transmitting HIV and/or HCV? Do you have concerns about the genetic risk of haemophilia? Did you think having children was impossible? For many people in our situation the choice of having children has not been on offer. For many, having children naturally has been a choice or accident as they are in any one else's life who doesn't live with HIV.

There have been recent news reports of improved sperm washing and assisted conception techniques and improved choices for people in our situation, but what is the reality? Is this something you want to think about? Are you getting the right information? Are you getting the right support to make the right decisions for yourself? Is funding a problem?

When Birchgrove was approached to consider writing an issue on conception we knew it wouldn't be easy as the strength of feelings and emotions around this topic are so acute for some. A number of people contacted us stating that although they had experience they could share with others, it was just too emotional and personal to write something about it.

As many of us are facing a changing life expectancy due to improved medication we also have changing needs, and many people are now looking towards the future and considering having children and a family. We hope that through the articles, personal experiences, reports and information we have collated on Conception and related topics that this edition of Birchgrove will give an opportunity for readers to become more informed on this topic.

We hope that we have approached this issue sensitively enough and understand that for some this will be difficult reading material.

...many people are
now looking
towards the future
and considering
having children
and a family.

contents...

Page 2-3

Reproductive Issues

Page 4

Top Tips

Page 4

Cost of Sperm Washing

Page 5

Sperm Washing in the UK

Page 6

Fear for HIV Motherhood Hopes

Page 7

Further Reading and Information

Page 8

**The Peg-Interferon Diary- The Story
Continues**

Page 9

Woodland Project Update

Page 10-11

Litigation News

Page 12

News in Scotland

Page 13

GMC Complaints

Page 14-15

Recombinant Factor VIII

Page 16-17

Snippets and Briefs

Page 18

Bob The Bleeder - Can He Fix It?

Page 19

Resources and Information

reproductive

The workshop commenced with an introductory talk by Lara Ovesiky, Haemophilia Nurse Specialist at the Haemophilia Centre, Churchill Hospital, Oxford.

Lara's presentation began with an overview of the implications of having or wanting to have children on HIV sero-discordant couples, where the haemophilic man is affected with HIV while his partner is HIV negative. Before even considering the question of possible transmission of HIV, she stressed the importance of providing the couple with relevant information on the effects of haemophilia, its inheritance, the possibilities of antenatal diagnosis, the consideration of selective abortion and the new reproductive opportunities, in order that an informed decision about proceeding with having a family can be made.

The main body of the presentation comprised an analysis of the latest statistics on the risk of transmission, with current estimates for unprotected vaginal intercourse, between an HIV+ man and a negative woman, carrying a 3-6 in a 1000 chance of transmission.

The risk of vertical transmission i.e. from HIV+ mother to child, is approx. 15-20%, with this risk increasing if the mother goes on to breast-feed. This may be reduced by 50% if the mother is treated with anti viral drugs during pregnancy, at delivery and to the baby once born, and may be halved again if the mother opts for Caesarean section.

Undetectable viral load and a high CD4 count in the infected male partner can offer a relatively safe option if linked to timed ovulatory intercourse. However despite the percentage risks for a significant number of couples it would not be appropriate or they are unwilling to abandon the use of condoms for fear of infecting their HIV negative partner.

A low rate of Hepatitis C transmission - 2.9% - meant that whilst this was still a factor for consideration when planning to have a family, it was not seen as crucial as HIV infectivity.

conception, such as 'sperm washing' or the use of 'donor sperm' available to HIV sero-discordant couples.

Briefly, the main options were:

Artificial Insemination with partner's "washed" sperm.

The technique is based on the assumption that HIV infective material is carried primarily in seminal fluid and not within sperm itself. The HIV infected seminal fluid is separated from the sperm cells by centrifugation (spinning) and a swim-up technique ("washing"). The washed sperm is then combined with artificial semen solution, tested for HIV viral load and, if negative, inseminated into the woman when she is ovulating. There is the possibility that the viral load of the washed sperm may test positive, in which case this procedure would need to be repeated.

Artificial insemination with donor sperm

In this situation, a donor, who is anonymous and will have had a number of screening tests and counselling himself, provides the sperm. This prepared sperm is then inseminated into the female when she is ovulating. For convenience and practicality the woman's ovulation is often regulated by the use of an ovulation inducing drug.

Intrauterine Insemination (IUI)

In this technique giving ovulation-inducing medication to the woman stimulates egg development and then prepared sperm is injected via a soft tube placed in the cervix.

Lara concluded with the observation that in the near future more assisted conception centres will accept HIV/HCV discordant couples on to their programmes. At present this treatment is not available under the National Health Service, but she feels sure that this will be challenged, since The European Convention of Human Rights Act came into effect. It States :- **'A Person Has The Right To Marry and To Found A Family.'** This will now make it easier for UK citizens to challenge the NHS on such an issue.

A number of questions were put to Lara from workshop attendees, with couples expressing

A report from a workshop held at "Something for the Weekend" 2002

by Mike O'Driscoll

despite the percentage risks for a significant number of couples it would not be appropriate or they are unwilling to abandon the use of condoms for fear of infecting their HIV negative partner.

...with careful monitoring of viral load and CD4 counts allied to the practise of intercourse at ovulation, some couples had managed to conceive without HIV transmission from male to female partner.

frustration at the current lack of accessibility to assisted conception programmes - particularly sperm washing - which remains unavailable in the UK through the NHS.

Some attendees shared their own experiences of starting a family, detailing how their frustrations with assisted conception programmes - the insistence on pre-treatment counselling for both partners, irrespective of all previous counselling sessions, the intrusion they felt into their personal lives, etc, had led to their deciding to go it alone. With careful monitoring of viral load and CD4 counts allied to the practise of intercourse at ovulation, some couples had managed to conceive without HIV transmission from male to female partner.

Mike O'Driscoll, a Haemophilic with HIV and HCV then gave a talk on his own experience of starting a family, the expansion of which was curtailed following HIV diagnosis in 1985. After the birth of his daughter, the options for assisted conception were much more limited than they have since become, leading to Mike and his wife exploring the option of adoption.

Having made a good initial impression regarding their suitability as prospective adopters, Mike outlined how the revelation of his HIV status changed the attitude of the adoption panel. The couple were subsequently turned down owing to the perceived terminal nature of the HIV diagnosis.

After some time had passed, the couple investigated the possibility of long-term fostering as a way in which to - if not expand their family - then at least to make use of the parenting skills they had developed with their daughter. Subsequently they contacted a private fostering agency, and, after a year spent training in various aspects of caring for children, they were approved as foster carers. Mike spoke about their experiences as carers since being approved, outlining both the positive and negative aspects of the job.

Among the latter he cited the difficulties one might encounter in dealing with the birth parents; the emotional baggage a child might

already have accumulated prior to placement; the problems arising from this last point - anger and aggression directed towards the carers, difficulties at school, in social behaviour, at fitting in with the carers' family, etc; the frustrations at the length of time it took to get the child's social services department to take action or even to arrive at decisions which might impact on the child's future.

On the positive side, he noted the close bond that can develop between carers and child; the immense satisfaction to be derived from seeing a damaged child make progress - for example, an undernourished child gaining weight, making progress at school, developing meaningful friendships with other children; learning to trust and respect rather than fear and be suspicious of adults; developing their own interests and taking pride in their own achievements.

Mike concluded his talk by emphasising the differences between adoption and fostering - with the latter, the legal responsibility for the child's welfare remains with either the birth parents or social services, depending on whether the child is subject to a protection order, whilst in the case of an adopted child, the adoptive parents take on the full parental responsibilities that would normally accrue to the birth parents.

He pointed out the need for prospective carers to find out as much information as they could about fostering prior to training, and for them to be realistic about the difficulties the job entailed. If at that point they remained undeterred, he said he was sure they would find it a very rewarding experience.

A few questions were raised from attendees, mainly asking for clarification on the differences between adoption and fostering. Having answered these, Mike offered as a first point of contact, the main telephone number the Fostering Network (formerly the National Foster Carers Association): 020 7620 6400

Email: info@fostering.net
Web site: www.fostering.net

issues

Some thoughts from a parent with experience of sperm washing....

- a) Doing it naturally is a choice most health professionals are scared of and will not help with, I suppose they do not want to be seen condoning what society sees as immoral behaviour.
- b) Surely it is better to have support and information. If that is the choice you make as it can help to understand when to have unprotected sex and stuff like having a sperm count and a woman checking to see if she is fertile....no point doing it if you 'aint got no tadpoles!
- c) The process of sperm washing is invasive, expensive and very clinical. OK as long as people know that but it can be soul destroying.
- d) Chances of a baby actually being conceived through sperm washing is very low, lower than by "normal" assisted conception.
- e) If you make a baby naturally are you going to find out the mothers HIV status if she is negative before conception? if so...will you terminate the pregnancy if she is positive?
- f) Is having a child who is HIV positive somehow the worst thing in the world or will you love that child as much as one who is negative and help them live with it?
- g) Other babies are born with stuff as bad and worse.
- h) Should you tell health carers if you are positive and making a baby naturally? Will they be OK and support you or will they freak out and suddenly the whole of the NHS knows and treats you like shit?
- i) Lots of people with haemophilia and HIV have had/are having babies through unprotected sex, they just do not tell people! One centre director I spoke to said he knows of at least 19 babies born to patients at his centre.
- j) People with haemophilia and HIV also have unprotected sex but once again do not tell many people!

the cost of sperm washing....

One of the main Assisted Conception Units for people with HIV is based at the Chelsea and Westminster Hospital in London. They produce a price list for their sperm washing programme and the current charge for a basic package is around £2,500. There may also be additional costs if fertility problems are identified as part of the process. Apart from this, if you don't live within easy reach of London, travel costs and overnight accommodation have to be taken into account. If you are living on income related benefits this may seem prohibitive but there are organisations that could assist you.

If you are a registrant of the Macfarlane Trust, the Trust will help with travel costs, accommodation, meals and other expenses incurred in order to access the treatment, however they will not pay for the treatment itself or any fertility tests arising.

Your Primary Care Trust (PCT) may fund your treatment. Most PCTs do not pay for fertility treatment, however it can be argued that sperm washing for people with HIV is not a fertility problem but an HIV prevention measure. Some Trusts may be willing to fund the treatment from their HIV prevention budget (if they have one!).

The problem with this is that disclosure of your status to the Primary Care Trust is necessary and some people do not want to take the risk of staff at their local Trust finding out that they have HIV.

If you do decide to try and get your PCT to fund the treatment, the Haemophilia Society can provide supporting letters on your behalf to pressurise the PCT and can also get other related organisations, like Birchgrove, Terrence Higgins Trust and the National AIDS Trust to do the same. This has been very effective in the past, for example in resolving a funding issue about hepatitis c treatment.

If you would like further information on sperm washing or any issue relating to HIV or HCV, please don't hesitate to contact me on FREEPHONE 0800 018 6068 or email: babs@haemophilia.org.uk

Babs Evans, HIV/HCV worker

...there may also be additional costs if fertility problems are identified as part of the process.