

## **Spring 2007 clinic data presentation**

### **Slide 1 - Heading**

Good morning, and thank you for the opportunity to present a summary of the most recent HFEA "Find a clinic" directory data.

### **Slide 2 – The value of the directory**

Until recently the directory was called the Patients Guide. This name now refers to the document available in a magazine format which introduces a patient or potential patient to the subject of infertility. The HFEA interactive Find a clinic directory which has been published on the HFEA web site in its current for the last two years provides extremely useful information for both patients and clinics. Previous success rates at a clinic are one of the many factors that patients regard as important when deciding where to go for infertility treatment. Obviously a patient's chances of success are dependant upon a great many factors, with age being the most obvious.

This is no such thing as an "average" patient. Success rates are only a guide to the clinics performance NOT guarantee of success for an individual. Looking at the average success rate for a clinic is not necessarily helpful as it will not tell you how likely you are to have successful treatment here. However success rates can prompt the patient to ask questions of the clinic about their performance - types of patients treated; whether their figures have improved, etc.

General trends in treatment outcomes over a long period show a small and continual improvement year on year. The figures aren't a guarantee for success at a given clinic for a given individual.

### **Slide 3 – Improving the quality of data**

It is important to acknowledge the huge amount of effort which both the clinics and the HFEA put into maximising the accuracy of the data, and we would like to thank the UK licensed Assisted Reproductive Technology clinics for their support.

The data has been verified by the clinics. It is the clinics responsibility to ensure data related to their centre is accurate and comprehensive. It's simply unfeasible for the HFEA to check over 45,000 treatments each year.

The data that is about to go live on the HFEA web site relates to treatments which took place in 2004. We recognise that this may feel like a long time ago but would remind everyone that a treatment which took place in December 2004 may have produced a child in September 2005. Allowing 3 months to report this outcome to the HFEA and up to 6 months to correct and confirm the data with an internal checking process followed by a 2 stage verification process would have meant that the earliest this data could have been published was the middle of 2006.

**Slide 4 – speeding up information/next release – timetable May 2007=2004, Winter 2007= 2005, Spring 2008=2006, Autumn 2008=2007 (fast as possible for LBR). Mention earlier availability of cycles and pregnancies.**

Better than anyone, we know the importance of ensuring accurate and comprehensive information but we also know the importance of information being as up to date as possible. To this end, we will be starting work immediately to improve the accuracy and verify the data relating to treatments in 2005, allowing publication later this year. The recent introduction of Electronic Data Interchange between the centres and HFEA which allows secure, instantaneous transmission of treatment data will allow this process to speed up significantly. Since introducing EDI over the last year, the accuracy of information being received has improved significantly. And as shown in the above slide we hope to move to a position whereby information related to Live Birth Rates is only a year old with treatment cycle and early pregnancy data available much sooner.

**Slide 5 – improvements to information**

The data which is available from today on the HFEA web site includes some format and content improvements when compared to the previous guide, with further changes to come in future directories.

Improvements to the depth and breadth of information given to patients and clinics include the following:-

1. We fully recognise that the number of people receiving treatment at a later age is growing year on year. These people want better information so we have included for the first time age bands for the 43-44 and over 44 age groups.
2. The publication of implantation rates for the first time which show early success rates whilst taking into account the number of embryos transferred. Some people see this as a fairer measure of clinic success than Live Birth rates as clinics less able to influence the later stages of pregnancy.
3. We know that multiples births are the single biggest risk of IVF, and it is widely acknowledged that the ideal outcome following IVF is the birth of a single healthy child. Education is important in tackling this problem. This year we have therefore introduced singleton birth rates per cycle started which give a measure of true success.
4. We know that a number of patients go through Pre-Implantation Genetic Screening in order to increase their chances of having a child. This year, for the first time, we have made available on-line PGS treatment and success data for the clinics which carry this out. As PGS patients are part of the same cohort of infertile people

seen by the clinics, this data is incorporated in the overall IVF data for the clinic.

### **Slide 6 – future improvements to information**

As part of our plan to continually improve the information given to patients and clinics, we plan to make available PGD related data in the next set of information we publish. We also plan to expand the search functionality, for example allowing patient's to search for satellite sites by location. We also wish to make available unverified cycle number data at an earlier stage.

A new data set is to be introduced later this year and will allow additional reporting such as cumulative live birth rates. By splitting the treatment and early outcome transactions, this will enable faster reporting of cycles to the HFEA.

### **Slide 7 – Clinic performance across UK**

The number of babies born through IVF continues to rise year on year. The data published today is based on 40,115 treatment cycles, given to 30,181 patients between 1<sup>st</sup> January 2004 and 31<sup>st</sup> December 2004. During this period there were 8,275 births, giving rise to 10,175 children.

The data published today for Donor Insemination is based on 6,888 treatment cycles, given to 2,951 patients between 1<sup>st</sup> January 2004 and 31<sup>st</sup> December 2004. During this period there were 708 births, giving rise to 750 children.

Our analysis of this large and significant data set shows us that statistically speaking, almost all UK clinics continue to operate at a similar level of performance, with just a very small number operating outside of the standard range. Where clinics are operating outside of this range, either above or below, the HFEA will seek an explanation.

We are aware that in addition to patients, clinics find the directory a tool to benchmark their own performance. Although patients are the main target audience for this directory, we also take into account the comments from the people working in the sector to continually improve its format and content.

In years gone by, the data was only available in paper format. Later, static copies of the paper documents were made available on-line. More recently, a search facility was introduced allowing patients to compare their nearest clinics. This interactive version has proved to be extremely popular with patients, many of whom are web literate. It also helps us to meet a number of eGovernment targets.

### **Slide 8 – Last year’s Find a clinic directory “hits”**

For those people without access to the Internet or a printer, we will continue to print on demand the relevant details when contacted through more

traditional methods of communication. An analysis of the last year's directory shows:-

- Pages downloaded/viewed over 1,000,000
- Visitors to the site 80,000
- Paper copies requested – less than 100

With this new directory, we have moved to presenting the information on a calendar year basis. This is in line with other national statistics and International Regulators in this field. Calendar year reporting for treatments simplifies the task for clinics to verify their data and is more meaningful for patients. This data is therefore not entirely new as it includes data previously reported between January and March 2004.

### **Slide 9 – The Context**

Of importance during the calendar year being reported is a change in policy guidance which was introduced in March 2004. The guidance to limit the number of embryos transferred for the under 40 age group would have affected the numbers slightly. However, the next directory to be published later this year relating to 2005 treatment is likely to show a significant reduction in 3 ET for the under 40's.

### **Slide 10 – National Treatments and outcomes in 1000's**

Nationally, the number of fresh IVF/ICSI treatment cycles increased by around 1500 cycles for the reporting period compared to the last directory,

which in turn was a rise of 1500 compared to the directory before that. The number of frozen cycles remains almost the same as the previous year.

National success rates for each type of treatment are similar for the previously reported period (April 2003-March 2004) which is unsurprising with only 9 previously unreported months included.

**Figure 1 – Comparing three reporting periods**

	FRESH IVF/ICSI		FROZEN IVF/ICSI		DI	
	Treatment Cycles	Live Birth Events	Treatment Cycles		Treatment Cycles	Live Birth Events
<b>2002/3</b>	27,100	6,100	7,000	1,000	7,400	800
<b>2003/4</b>	28,500	6,500	7,000	1,100	7,300	800
<b>2004</b>	30,200	6,700	7,300	1,100	6,900	700

**Slide 11 – Implantation rate example showing the differences/benefit**

Previously the emphasis of our reporting has been on live birth rates. We have now moved the emphasis onto Implantation rates.

An implantation rate is an alternative form of pregnancy rate which takes into account the risks associated with multiple embryo transfer. Some people regard this as a fairer measure of a clinic’s success as once an embryo has implanted the clinic is less able to control the progress of the pregnancy.

Implantation rates are normally calculated by dividing the numbers of gestational sacs by the

number of embryos transferred. The HFEA has to date collected fetal hearts instead of sacs but in virtually all cases this is the same and would affect clinics equally.

## **Slide 12 – National comparison**

This table shows the difference between the various methods calculations of success rates for each age band at a national level.

## **Slide 13, 14 & 15 – Example search**

The HFEA Find a clinic directory is not about league tables. It allows patients to produce tailored information to reflect their individual condition and circumstances. By entering a postcode or region you will see a list of centres offered. If you then click on a centre it takes you to the detailed entry for that centre. Within that page a series of tabs, one of which is the IVF/ICSI data in the new format as shown.

In summary, a huge amount of effort is spent in making the data as accurate as possible though it is important to remember that the data is verified by the individual clinics.

Thank you for your time.