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EDITORIAL

On the necessity of monitoring ART

Karl Nygren for the International Committee on the Monitoring of ART (ICMART)

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Current data on the safety and efficacy of ART, from many parts of the world including the Middle East, provide convincing evidence of the necessity to understand clearly and to follow continuously the outcomes of ART activities.

Why is this necessary?

Because without a continuous surveillance, confidence in ART will be eroded and undermined. ART does have, still, safety problems and risks that need to be described and evaluated so that current clinical policies and laboratory procedures can be revised, if necessary. ART is, still, controversial to some, mainly because uncertainly about its safety. Confidence in ART is needed for the couples to be treated but also for the professionals who provide the treatment and for society at large, for legislators and resource allocators.

It would, in fact, be very unwise and counter-productive and indeed unethical
not to monitor the safety and efficacy of ART.

Both aspects need to be covered, both efficacy and safety, because success and treatment benefits rely on both factors and on a reasonable balance between them. Also, an evaluation against cost and time should be included.

The data collection techniques for ART monitoring differs between efficacy indicators and most of the safety indicators. Resources for data collection differs in different settings. For efficacy assessment the creation of an IVF register, collecting data from the IVF clinics in the area, is a workable option.

Many countries have such IVF registers already today while other countries are in the process of setting up such registers.

The perhaps most important indicator for the safety of IVF-children, which is the incidence of multiple pregnancy and delivery, can also be covered by an IVF register, whereas other safety indicators, like cerebral palsy and other medical conditions which are not always evident at birth, cannot be collected by an IVF register collecting data only from the IVF clinics themselves. Typically, many IVF clinics actually lose track of their pregnant patients after the first trimester. Therefore, for several safety indicators, population based health registers which exist in some countries can be used for cross linkage. Examples include birth-registers, cancer-registers, malformation-registers and more. In countries

lacking such registers, specific research projects are needed for the follow-up of the IVF-children.

These difficulties do not give reason, however, not to start off with an IVF register with data collected from the IVF clinics.

For the protection of their own operations, many clinics no not want to disclose their results openly. Clinics compete with "success-rates", which typically do not give the whole story. Therefore, many registers present data without identifying the different clinics. This is acceptable at present but in the long run openness is a better choice. Again, the reason is confidence building and maintenance. Secrecy leads to suspicion.

Ideally, each clinic should report their data only once to their National or their Regional register, which then reports to the ICMART for the World Report.

Ideally, all clinics should use the same forms and the same definitions of terminology.

Following an ICMART/WHO workshop in Cairo in October of 2003, a Middle East IVF Register was established, hopefully with full coverage of the area and with full international cooperation and participation. Dr. Ragaa Mansour from Cairo was elected to run the register.

This is a very important and significant and indeed necessary step for building and maintaining confidence in ART.