**A call for a national ART registry**

**To the Editor:** More than thirty years have passed since the first successful in vitro fertilization (IVF) was performed in 1978 and since then the use of techniques of assisted reproductive technology (ART) has increased. Collection of national data for the US and Canada was launched in 1989, and in 1992 the US government passed the Fertility Clinic Success Rate and Certification Act, which requires the Centers for Disease Control and Prevention (CDC) to publish pregnancy success rates for ART performed in fertility clinics in the US. Accordingly, all clinics in which ART is performed are required by law to submit their results to the government.

In addition, an overview of the world practice of ART since 1989 has been produced by the International Committee Monitoring Assisted Reproductive Technology (ICMART). ICMART collects and analyzes data from national registries or individual ART units around the world, from which an annual report is produced. Data collected represent over 2/3 of ART cycles performed globally.

Additionally, IVF registry reports from the Middle East are prepared annually by the Middle East Fertility Society (MEFS).

To truly serve the needs of the country, it is essential to follow global trends and outcomes and obtain national data such as that collected by the CDC in the US. Only when a national registry is in place can a true understanding of the status of ART in Saudi Arabia be acquired. From that understanding, strategies can be developed for assuring that state-of-the-art services are provided and research plans can be formulated that are customized for the patient population.

We propose to establish a voluntary nationwide ART registry in Saudi Arabia, and collect comprehensive data on all procedures on a standard data form from which annual reports will be prepared. Achieving the anticipated registry will help us collect data on the long-term outcome for a cost-effective reduction in NICU admissions that exerts a huge burden on all NICU centers in the country.

**ART registry stakeholders**

The importance of ART registries extends to numerous stakeholders, which include couples who will benefit from information acquired about treatment strategies and choices, in addition to the clinics who will benefit at the national and clinic level from feedback and policy adjustments. Furthermore, industry and academia will acquire salient information that can drive research and development. Regulators will have the information needed to make evidence-based ethical decisions and legal regulations. The allocators of resources will also provide benefits to the public at large.

**Digitalization**

Data collection should be digitized, which will require creation of a website to log the patients using their national identification numbers to accurately trace fetuses and outcomes. This will give actual data on success rates every step of the way. Patient identification will be anonymized on the registry spreadsheet compiled at the ART centers; that is, only arbitrary ID numbers will be in the database. Medical registry data is typically exempt from informed consent and, per many internationally accepted standards (Stanford 2008), informed consent (IC) can be waived.

The Saudi Arabian Registry (SAR) will provide invaluable data for the ART industry in Saudi Arabia with information on the patient base, services offered, volume of activity, and outcomes achieved. Comparisons will be possible among small, large, private, and governmental clinics. The results will assure that ART specialists in the country are aware of the status of ART in Saudi Arabia. SAR can be used to establish standards and investigate anomalies.

We also anticipate that information obtained on the enrolment questionnaire will provide the basis for an informative and valuable publication summarizing ART technology in Saudi Arabia. We plan to participate in the ICMART and MEFS registries, allowing comparison between Saudi Arabia and other regions and countries.

Finally, we expect this initial venture will provide evidence that, indeed, information sharing can be achieved and be beneficial to ART in Saudi Arabia. Accordingly, we envision that the Saudi Health Council, which is an independent body from the Ministry, will support making of the SAR as an official, mandated registry.

**Acknowledgment**

Ms Valerie Zimmerman, Dr. Solaiman Al–Obaid, Sahar Lary, MD, Gamar Salim, MD, Jawhra Al-Zubeidi, MD, the REIMD lab team, and Alaa Ghubian from IT at KFMC and Ouhoud Kaddour, BSc, Abdalla Ibrahim Salih, MD, FRCOG Mohammed Agdi, MD, Saad Hamad Alhassan, FRCOG, MMSci (ART), Muhammed Bugnah, MD

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