

HFEA Announcement – Closure of Donor Conceived Register



Dear Registrants,

On Friday the 9th March the NGDT learned that the Human Fertilisation and Embryology Authority have decided to close the Donor Conceived Register for which they are the funders.

On Saturday 14th April 1200 there will be an emergency meeting of the Registrant's Panel which will be attended by the HFEA who will be seeking to explain and consult with Registrants regarding the reasoning behind their decision. Details will follow shortly about location, but it is likely to be at the usual location near Waterloo.

There follows a copy of HFEA's statement, as well as the response of the NGDT, and Emma Cresswell, Chair of the DCR Registrants Panel.

Yours Sincerely,

Andrew Waters

Deputy Chair of NGDT

1. HFEA statement – Fri 17th March 2018:

I am writing on behalf of the HFEA to confirm the outcome of the recent tender exercise. You'll be aware that we recently went to market for the DCR service. We received one bid and that bid did not meet the standards we had specified and on that basis, we were unable to award the contract. The current contract with NGDT comes to an end on 31st May 2018.

We have carefully considered the options and on reflection, we now feel there are alternative ways in which support groups can form, removing the requirement for a central body to co-ordinate the group. The DNA testing market has progressed in recent years and it is now possible for tests to be commissioned independently without the need for a central body to oversee this. On that basis, our intention is that funding for the service should cease on 31st May 2018 when the current contract comes to an end. It may be possible to agree a longer transitional period funded by the HFEA and this may include the service being delivered in a different way from June, for example via self-management.

We would appreciate feedback on the above and there are two ways in which you can do this. Firstly, by email using dan.howard@hfea.gov.uk. Secondly, we would appreciate the opportunity to meet with the panel and details will be confirmed shortly.

Lastly, we are very grateful to the NGDT for running the service successfully for many years.

Dan

Dan Howard

Chief Information Officer

Human Fertilisation and Embryology Authority

www.hfea.gov.uk

@HFEA

2. Donor Conceived Register: Statement by the Emma Cresswell (Chair of DCR Panel)

It is with great personal disappointment that I must inform registrants that today we have received news from the HFEA that following a tender process to compete provision of the Register they have made the decision to cease funding for DCR as of 31st May 2018. Due to the short notice we are asking for an extension to this date and are arranging an emergency meeting of the Donor Conceived Registrants Panel in London on April 14th (time and location TBC) to discuss this with a representative of the HFEA.

The Panel meeting will also discuss how this affects registrants and what action we can take. Please can anyone who is able to attend let Pip know on info@donorconceivedregister.org.uk). If there are any opinions, thoughts, questions or suggestions regarding the matter please send these to Pip to collate for the meeting. I am afraid this is all the information we have currently, and we are unable to respond to direct queries regarding the HFEA's position but will attempt to raise any queries you have either at the meeting or in writing. We will share any response with Registrants after the meeting via Facebook and email.

Kind regards
Emma Cresswell
Chair of Donor Conceived Registrants Panel

3. Donor Conceived Register: Statement by the National Gamete Donation Trust

The Human Fertilisation & Embryology Authority (HFEA) today announced its decision to cease funding the Donor Conceived Register with effect from 31st May 2018. There has been no consultation about this decision with either the NGDT or with registrants. This is a tremendous blow to a much-valued service that has been in operation since 2004 and which continues to grow.

The NGDT has been managing the Register for the past five years, latterly under contract with the HFEA, and had hoped to continue doing so. We therefore submitted a bid when HFEA put the Register out to tender in December 2017. However, we could not agree to a number of HFEA's contractual requirements, including legal liabilities, that NGDT as a small charity could not afford and which we considered unfair and egregious. Although we were the only bidders, we were unsuccessful.

We knew our bid might not succeed, but HFEA's decision to abandon the DCR came as a complete surprise. We have urged the HFEA to at least keep the Register in operation longer than 31st May to allow registrants time to explore alternatives.

In the circumstances, we have no choice other than to begin the process of winding down the DCR, albeit with considerable sadness. This means that, as of today, we will not be accepting new registrants.

A number of registrants have DNA samples currently with King's College. We are working with King's College to best ensure that all work is completed within this short timeframe.

We are waiting on HFEA for a decision about what should happen to the DNA database. We are also in discussion with the DCR Registrants' Panel about next steps.

Charles Lister

Chair of NGDT Board of Trustees

16th March 2018