



## **Victorian Adoption Network for Information and Self Help**

SUBMISSION TO VICTORIAN GOVERNMENT'S DISCUSSION PAPER

### ***'A right to know your identity'***

***Giving donor-conceived people the right to access  
information identifying their donor.***

To:

The Assisted Reproductive Treatment Policy Manager  
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On behalf of

The VANISH Committee of Management

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## **ABOUT VANISH**

The Victorian Adoption Network for Information and Self Help (VANISH) has more than 26 years' experience providing family search and support services to people who have been separated from birth relatives through adoption, intercountry adoption and/or state wardship. In recent years, VANISH has extended its focus, and a limited degree of service, to people impacted by donor conception: donor-conceived people, former donors and the families of both. This includes working with the Victorian Assisted Reproductive Treatment Authority (VARTA) in providing a support group for donor-conceived people and provision, through Monash IVF, on a fee-for service basis, of search services on behalf of adults with a personal experience of donor conception who are attempting to locate their donors. VANISH is also in the process of setting up a similar search service with Melbourne IVF. In the past VANISH provided searches for the organisation that preceded VARTA. VANISH recognises and highlights the strong parallels between the adoption experience of confusion, loss and grief and that of people affected by donor conception.

VANISH strongly supports the Andrews Government initiatives to further reform law and practice surrounding support and assistance for people affected by donor conception. In particular, VANISH supports the implementation of measures to enable searching for donors by virtue of donor conception. We look forward to working in conjunction with VARTA, 'the Authority' to offer a high standard 'search and support' service.

In supporting the Government's initiatives in this regard, VANISH notes and emphasises the importance of providing adequate and ongoing funding for these services. We elaborate on this aspect of service provision in our response below.

## **THE GOVERNMENT'S PROPOSED AMENDMENTS**

VANISH wholeheartedly agrees that knowledge about parentage and genetic and cultural heritage contributes significantly to a person's sense of identity. VANISH thus strongly supports the right of all donor-conceived people to access identifying information about their donors.

VANISH strongly agrees that it is necessary to provide a supportive and protective framework for all donor conception stakeholders and looks forward to offering such a service to donor-conceived people who are searching for their donors, and donors who are searching for their now adult children and their families.

## **IMPLEMENTING THE GOVERNMENT'S COMMITMENT**

VANISH strongly supports the Government's commitment to make purposeful reform in this area of public policy and practice, and to do so in a meaningful and sensitive way. We note that the Government has publicly recognised the particular experience and knowledge which VANISH is able to bring to consideration of these matters. We welcome the opportunity to be a part of the Government's foresightful action in this area.

VANISH also strongly supports and endorses the principles and considerations which have been articulated as underpinning the development of the Government's approach to implementing its commitment.

- 1. The law should, as far as possible, treat all donor-conceived people consistently and equally, regardless of when the donations that led to their conception were made.*
- 2. It is critical to the welfare and interests of donor-conceived people – as it is to all people – that they have the opportunity to know their genetic identity.*
- 3. Consideration should be given to the impact of releasing donors’ identifying information on donors and their wider families, as well as on donor recipient parents.*
- 4. The rights conferred by the law on donor-conceived people should be meaningful and, as far as practicable, able to be exercised.*
- 5. As far as practicable, legislation should not place undue regulatory burden on medical practitioners and health services.*

This is a complex area of policy and practice. Seeking broad community input, as the Government is doing in this instance, is to be applauded. Such input will be critical to achieving engagement and commitment from all key stakeholders – in particular donor- conceived people, sperm donors and egg donors, IVF clinics and practitioners, and others who are key players in the field.

VANISH puts forward the following comments and submissions regarding the major points canvassed in the Discussion Paper.

### **PROVISION OF SERVICES: ‘One Door in’ Service**

VANISH strongly supports an accessible, easily navigable service system that provides adequate support for people seeking and receiving information. VANISH broadly agrees with the Government’s proposed amendments which would establish ‘the Authority’ (VARTA) as the ‘one door in’ service provider for any person seeking information about donor conception, and that the operation of the Central Register and the Voluntary Register be transferred to ‘the Authority’.

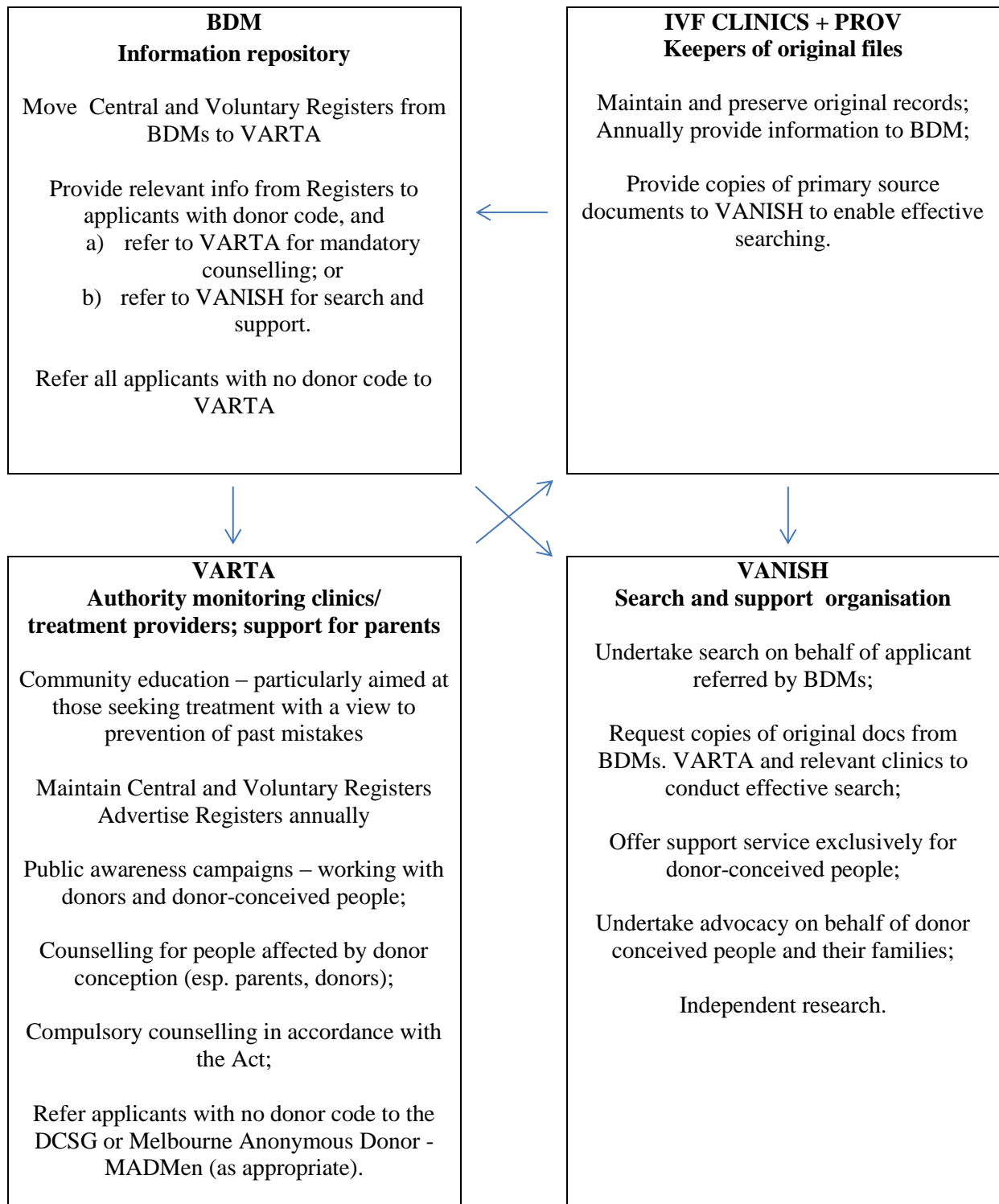
However, VANISH and its donor-conceived members have expressed reservations about this model, as they believe there is a conflict of interest when the public statutory body responsible for regulating the IVF industry simultaneously provides services to donor-conceived persons. There is a strong parallel here, as one of the main reasons for the establishment of VANISH was the demand for an independent organisation to provide a ‘search and support’ service for adopted people, one which had not been involved in arranging past adoptions. In this respect, VANISH endorses the Government’s commitment to ensuring that the entity managing the disclosure of personal and health information should be an experienced, non-partisan body, operating within a framework of strong public accountability.

VANISH strongly agrees that ‘the Authority’ should access the expertise of an approved specialist provider to deliver a ‘search and support service’. Further, we submit that VANISH is strongly placed to undertake this task. In order to do so, VANISH would require unfettered access to the relevant information, where it exists, and a direct and accessible working relationship with the Victorian Registry of Births, Deaths and Marriages (BDM).

VANISH agrees that it is necessary to have clear lines of responsibility and recommends that:

- (a) legislation explicitly nominate VANISH as the approved service provider; and
- (b) clauses be included to explicitly outline how information is to be shared between the Authority, BDM and the approved search provider.

Further, VANISH puts forward the following proposed service model:



## **DONOR LINKING COLLECTION**

VANISH supports the establishment of a Donor Linking Collection to be managed by ‘the Authority’ to extend and enhance the service, but cautions against the redundancy of the Voluntary Register. VANISH notes that there is still a need for the Voluntary Register, particularly for those donor-conceived people and donors who have no records and are therefore unable to access the Central Register.

VANISH strongly supports ‘the Authority’ providing information and ongoing public education about donor conception and Donor Linking in the community. Broad based and better understanding of the issues regarding donor conception is of critical importance to the welfare of those affected by these practices.

## **INFORMATION DISCLOSURE AND CONTACT PROCESS**

VANISH strongly supports the release of donor identifying information to donor-conceived people. In so doing, VANISH points to the close parallel with the experience of adoption. It is a fundamental human right to have access to accurate information regarding one’s conception and birth, including all donors, parent/s and genetic material. Without such information, there is often confusion, loss and grief which lead to problems with identity and future relationships. This need to know from whence one comes appears to be a very deep and universal need and extends to knowing one’s siblings and members of one’s extended family. Also, there can be medical reasons why this information should be available. Further VANISH believes it and all other stakeholders should actively work to increase the understanding of the public about the necessity for honest, transparent information about donor conception and the opportunity for children and adults to have appropriate connection with their donors.

## **CONTACT PREFERENCES**

VANISH notes that on 19 August 2015, the Government repealed ‘contact statements’ and penalties from the 2013 Amendment to the *Adoption Act* (1984). It seems ironic that on the one hand these provision are being removed for one group affected by separation from birth family while, at the same time, they are being newly applied to another such group.

Such ‘contact statements’ and related penalties, were included in the reform of adoption legislation for the same reasons that they are apparently proposed here, i.e. to protect adopted children (now adults) from unwanted contact from their (natural) parents. Experience in this respect has been that the ‘contact statements’ were placed in only 16 cases, and 9 of them provided for partial contact. No breaches of the penalty by (natural) parents occurred. VANISH, from 26 years of experience, believes that all adults appear quite able to say ‘no’ when that is their wish. However, many adopted people have been surprised to learn that the information provided in their adoption records was often inaccurate – leading them to have changed perceptions and a new openness about contact from a birth relative.

While noting and endorsing the Government’s view, parties may take time to adapt to the changes that may follow the release of identifying information. VANISH does not support the application of

‘contact preferences’. Such a provision carries with it an implication of potential ill-intent or inappropriate actions on the part of those (either donor-conceived people or donors) seeking identifying information and contact. From VANISH’s perspective, there is no basis for such implications in the 26 years we have been working in this area.

## **UNDERTAKINGS AND ASSOCIATED PENALITES**

VANISH does not support this proposal – for the reasons advanced above.

VANISH further notes that a similar penalty has just been removed from the *Adoption Act* 1984, as it was considered to be unnecessary and was never used. VANISH views the penalty proposed here as harsh and unnecessary; it conveys negative and punitive messages to those who may seek identifying information about their progenitors or offspring.

## **LOCATING AND VERIFYING RECORDS**

VANISH strongly supports the proposal for donor-conceived people to be offered counselling and support in cases where records cannot be located. We note that donors from the pre-1988 period may, in some instances, require and/or value similar support. VANISH is able to offer support and counselling as an alternative to those who do not wish to use the services of ‘the Authority’ due to a perceived conflict of interest.

## **IF THE DONOR CANNOT BE FOUND**

VANISH believes that there is a particular need for ongoing support and counselling for those undertaking searches – particularly where the search is unsuccessful often causing ongoing confusion, loss and grief. Access to a support group for donor-conceived people, which VANISH currently provides, can also be of benefit.

## **LOST RECORDS**

Further, and importantly, VANISH proposes that active consideration be given to measures which may alleviate the difficulty created by lost/destroyed records, with clear information on all possible sources of information available to all those who search in order that they may be assured that all efforts to locate their records have been undertaken.

On occasion, VANISH will need to utilise segmented and indirect records in order to make connections in cases where primary donor records do not exist. In this latter regard, VANISH has long and deep experience in conducting adoption and former ward searches for birth relatives – and has an impressive success rate in this work. VANISH is thus well positioned and prepared to both advise on, and work on, the establishment and/or extension of such search services.

## **DNA TESTING SERVICES**

VANISH advocates the establishment of a Government supported, and funded, DNA testing service for donor-conceived people and donors in order that such services should be easily accessible to those parties. In making this case, VANISH draws the attention of the Government to the Recommendation (12 7.76) of the *2011 Senate Legal and Constitutional Affairs References Committee Donor conception*

*practices in Australia*, which recommended that any voluntary registers incorporate a DNA databank in order to enable donors and donor-conceived individuals to have their details placed on the register for possible matching, in circumstances where records relating to their identities have been destroyed.

## **CURRENT VANISH SEARCH SERVICE**

VANISH is funded through the Department of Health and Human Services to provide a free ‘search and support’ service to people with a personal experience of separation through adoption from a parent and/or child. A similar government funded service is provided to another group of Victorians who experienced separation from birth relatives through the child removal practices of state wardship. This is not the case with donor conception searches, as they are unfunded and VANISH is only able to undertake them on a fee for service basis. This discrimination is difficult for donor-conceived people to understand and VANISH believes it is crucial that donor-conceived people are provided with a free ‘search and support’ service, just as is provided to adopted people, (natural) parents and former wards of state. VANISH proposes that specific funding be allocated to VANISH to undertake searching and support on behalf of donor-conceived adults and their families, and that VANISH be the designated service provider working in this regard with ‘the Authority’.

Currently, for a fee, the VANISH service has been extended to adults with a personal experience of donor conception where the request is made by Monash IVF or Melbourne IVF on their behalf. Currently this fee is \$165.00 (including GST) per search and it is reviewed annually. VANISH would propose extending this service on a free basis to respond to direct requests for ‘search and support’ from people who are donor-conceived i.e., when referred from BDMs or self-referred. This would avoid the dissatisfaction expressed by donor-conceived people as to why they are charged a fee and natural parents and/or adopted people are not.

VANISH envisages working collaboratively with BDM, VARTA, and the IVF clinics to ensure that information and experience is appropriately and efficiently shared, so that the most effective and well supported search service can be provided by our experienced staff.

## **RESEARCH**

VANISH recognises the need for independent research to be undertaken in the field of donor conception, and has previously raised concerns that current and existing research carries a pro-donor conception slant, with prominent researchers being connected to the ART industry.

VANISH recommends that funding be provided to allow for other independent interested research groups, as well as independent researchers, to expand the knowledge base and ease apprehensions of bias which currently exist.

## **ADVOCACY**

VANISH notes that VARTA has been unable to advocate on behalf of donor-conceived people due to its position as a government statutory body.

Donor-conceived people and donors are represented on the VANISH Committee of Management, VANISH membership and in VANISH support groups for donor-conceived people. VANISH, an

independent community organisation with 26 years of experience advocating on behalf of those affected by past adoption practices, is well placed to continue to provide advocacy on behalf of the donor conception community.

## **LANGUAGE/NOMENCLATURE**

As has been the case in the past with adoption, the language used to refer to donor-conceived people is unclear, inconsistent and at times cumbersome. For example, are donor-conceived people referred to by that nomenclature, or ‘donor/donated children’, or some other term? And are sperm or egg donors referred to as ‘donors’, ‘donor fathers/mothers’, ‘biological fathers/mothers’, ‘progenitors’? VANISH proposes that this matter be given consideration, with a view to developing an accepted and standardised form of language to be used in this area, and that this matter be added to the remit of ‘the Authority’. VANISH has experience in traversing this fraught territory in the case of work in post-adoption and ‘forced’ adoption, and has expertise to offer in this regard.

## **SERVICES TO, AND SUPPORT FOR, DONORS, AS WELL AS DONOR CONCEIVED PEOPLE**

VANISH notes that the major focus of the Discussion Paper is directed to issues concerning donor-conceived people. This is understandable, as the major thrust of this, and preceding, changes to legislation have been concerned with enabling donor-conceived people to have proper access to information about their sperm donors or egg donors. At the same time, it is important, too, that donors, especially from those who donated gametes prior to the 1988 legislative changes, are offered appropriate support. VANISH notes that the amendments to the Assisted Reproductive Treatment Act 2008 provides pre-1988 donors with the same rights to access identifying information about their donors as are provided for donor-conceived people. In this context, outreach, information and support services are just as important to donors as they are to donor-conceived people. VANISH notes the work undertaken by VARTA in recognition of this need and strongly supports that work. Subject to provision of suitable funding, VANISH is willing and interested in playing an appropriate and defined part in such services.

## **CONCLUDING COMMENT**

VANISH has more than 26 years’ experience assisting and supporting people searching for parent/s, adopted daughters and sons, siblings and relatives who have been separated by adoption, intercountry adoption and/or state wardship. What we believe sets VANISH apart is that the staff team always includes a balance of professionals and those who have a personal experience of adoption and/or donor conception and are therefore able to offer appropriate assistance and support with empathy and respect. VANISH is in an ideal position, subject to appropriate funding, to provide a similar service to donor-conceived people. In doing so VANISH would work in close collaboration with ‘the Authority’.

VANISH concludes this submission by noting and commending the Government’s actions in progressing reform to donor conception policy and practice. This work places Victoria at the forefront, nationally and internationally, in this regard. The opportunity here exists to achieve further significant reform. We encourage the Government to take that opportunity.