

# 法改正のために私が歩んできた道

## A Personal Journey for Legislative Change



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### 要 旨

法律の改正を求め、ロビー活動を行うことは簡単なことではなく、多くの場合、何年ものたいへんな努力が必要です。たった一人で達成できる場合もありますが、多くの場合、人々が集まりグループとなって具体的にに取り組むことが必要です。変化を生み出すために必要なことは、たった一つの出来事から生まれるのではなく、人々の人生の中で起るたくさん出来事や不公平だと思われるようなことから生じます。私は、自分がオーストラリアの法律や政策のさまざまな変更についての関わってきたかについて、私個人が歩んできた道をみなさんに紹介したいと思います。

このロビー活動は、南オーストラリア州の生殖補助医療法の法改正を求める中で最高潮に達しました。提供配偶子での出生者が自分たちの生物学的父や母、すなわち配偶子ドナーの氏名や住所を含む情報へのアクセスを、いつ生まれたかに関係なく許可するという内容を入れることを求めて、数十年にわたる配偶子ドナーの匿名性を覆そうと議論されました。提案された修正案の内容、すなわちそのようなドナー情報への遡及的アクセスを法律で認めるのは、南オーストラリア州が世界で 2 番目になります。このような改正は、オーストラリアのヴィクトリア州でナレル法として導入された先駆的な法律に習い、それに基づいて構築されています。

何十年にもわたってドナーを秘密にし、それを文化としてきたことに反対して起こった世界各地の法律の変更が起こった経緯や、不妊クリニックや不妊治療クリニックや臨床医などの強力な利害関係者のグループのよるロビー活動を調べることで、他の法域でも法改正を達成するためにしてきた経緯や手順を理解できます。

## Abstract

Advocating and lobbying for changes in legislation is rarely a simple task, often taking many years of hard work. Sometimes it can be achieved by a single person, but more often than not, it requires a concerted effort by a group of people. Quite often, their need to create change will not be born out of a single event but will arise out of a multitude of events or perceived injustices during their lives. Damian Adams will take you on a personal journey of how he has been involved in various changes to legislation and policy in Australia.

This lobbying has culminated in recent amendments to the South Australian Assisted Reproductive Treatment Act and current amendments being debated that would overturn decades of gamete donor anonymity by granting donor-conceived adults' retrospective access to identifying information on their biological father/mother, the donor. The proposed amendments would be only the second time that such retrospective access has been granted in the world. These amendments would be following and building on pioneering legislation introduced in Victoria, Australia, as Narelle's Law.

By examining how changes in the law have occurred around the world, and which have gone against decades of secrecy, culture, and lobbying by powerful interest groups such as fertility clinics and clinicians, we can understand some of the processes and steps required to attempt to change the law in other jurisdictions.

## 報 告

今日お話しするのはオーストラリアと南オーストラリア州での法律改正を求めてきた私の個人的な旅のことです。

### 私について

まず、私は 1973 年、南オーストラリア州の公立病院で提供精子で生まれました。その病院は 1972 年に南オーストラリア州ではじめて精子バンクを持った病院です。私は子どもの頃から提供精子で生まれたと分かっていました。それは当時とても珍しいことで、普通の親は秘密にしておきますが、私の親は、出自を知っていたほうが私のためになると思って話してくれていました。子どもである私にはそれが問題ではありませんでした。学校もあったし、子どもなりに忙しく、精子提供者、つまり生物学的な父についても別に興味はありませんでした。

オーストラリアでは、2004 年以降に生まれた人たちについては、生物学上の親が特定できることになりました。ただヴィクトリア州の場合は例外で、それ以前からドナーの特定情報を得ることが可能でしたが、私のような 2004 年以前にヴィクトリア州以外で生まれた人たちはドナーを特定するための情報にアクセスはできませんでした。南オーストラリア州では、法律で、ドナーが特定されないような情報についてはアクセスができるということでしたので、15 歳の時にアクセスをしようと決心しました。自分のアイデンティティについて悩んでいたからです。それがトラウマのようなつらい気持ちだったので、ドナーが誰かは特定ができないけれども情報を探すこ

とにしました。クリニックに連絡しましたが僕の記録は処分されたといわれました。

それから 5 年が経過をし、20 歳になったときに提供者に関する健康情報が必要となりました。私が通っていた医師が当時私のかかっていた病気の診断が見つからないということがあったからです。そこで、そのクリニックに再度連絡をとったら、話が変わりました。記録は紛失したのであって処分したわけではないと。それで変だなと思ひまして、情報公開法に基づいて情報提供請求を行いました。オーストラリアではこれは強制力がある要請でして、それらの記録は母に関する記録であって、もともとは母のものですから情報公開請求権があるわけです。結局、クリニックでの記録は存在していて見つけ出すことができました。つまり、彼らは嘘をついていたわけです。オーストラリアの他の出生者も同じ経験をしています。クリニックに聞くと嘘をつかれ、情報公開法で請求すると嘘がはっきりするんです。

ただ、情報があると言いますが、特定ができる情報も、特定できない情報もドナー番号で一致する記録がないと言われました。その後 2003 年に自分の家族ができました。個人としては自分のアイデンティティに悩んでいたたり、健康上の問題などがあったけれども、匿名での精子提供には賛成していました。何だか生まれながらの負い目のような気持ち、つまり、賛成しないと自分の存在理由がなくなるという思いからです。しかし、それについてはいろいろな考えがあり一筋縄ではありません。

ただ、私の考え方が 180 度、変わったのは娘が生まれたことでした。私自身のおもかげを娘に見ることができたのです。娘の父親になったことを実感することができました。だけど、私はそんな関係を生みの父には確認ができませんでしたし、それで突然思ったのです。自分の生物学的な親とは、自分の娘とどのような関係は感じられるのかと。そこから自分の情報公開を求める旅が始まりました。私自身の提供者の情報は得られないとしても、他の出生者が同じトラウマ、同じ苦しみを経験しなくて済むように何かできるのではないかと考えて、権利擁護活動（アドボカシー）を行うことにしました。

## 私が行ってきた権利擁護活動

ここから先の発表は、一部のアドボカシーの活動を紹介いたします。オーストラリアのすべての問い合わせと法的レビューを網羅してはおりませんが、ご参考までにどんなことが起こっていたかの少し紹介したいと思います。

娘が生まれてから、出自を知る権利のキャンペーンを始めまして、例えば、オーストラリア人権委員会、あるいは、連邦保健・高齢化大臣、南オーストラリア州の州首相、あるいは、この州の保健大臣 2 人、また、オーストラリアの上院、下院、旧議員の全ての議員に対して書簡を出しました。返事をくれたのはボブ・サッチ議員だけでした。彼は私の訴えを南オーストラリア州議会に持ち込んでくれまして、2009 年に法改正され、南オーストラリア州で任意登録（ボランティアレジスター）が導入されました。しかし、残念ながら、ここで大臣が登録を義務化するのではなく、任意でもいいということにとどまりました。そのため、今にいたるまで提供者登録がありません。

その翌年、私はサポートグループのメンバーや、患者であった夫婦、この関係者と一緒に連邦議会に請願書を提出しました。そして、第三者のかかわる生殖医療に関してオーストラリアの上

院で審議してもらえることになりました。その審議の結果、オーストラリアでは配偶子提供による出生は州法に準拠しており、州ごとに異なる法律があるため、全国的に一貫した法律を設けることを含む多数の勧告がありました。提供配偶子で出生したの人の登録と、そうした人々の保護と福祉の必要性が示唆されました。匿名性を禁止し、ドナーの条件を盛り込むことを提案・推奨しました。それは合計 30 以上の他の推奨事項でした。しかし、健康法（Health Law）は州が管轄している法律であるため、この連邦議会上院での審議はほとんど意味がありませんでした。翌年、ヴィクトリア州で審議が行われました。当時の審議委員会の委員長は、初めから現状を変えないし、ドナーを特定できる情報の提供についても認めるつもりはなかったと、後に認めました。しかし、彼らは提供型医療で生まれた人々の話を聞いてくれました。私たちの痛み、トラウマ、苦しみに耳を傾けてくれました。私たちが泣いたときには、彼らも泣いてくれました。

後に、調査委員会の委員長が、委員会としては出自を知る権利より、提供者で匿名でいたいという人を優先するべきであると強く思っていたと述べていました。でも調査委員会は、情報を特定するために過去にさかのぼってアクセスするという世界初の勧告をしました。法律を変えるには時間がかかるものです。施行されたのは 2015 年でした。ナレル法と呼ばれています。これは、末期の大腸がんで苦しんでいたナレル・グリッチという女性が調査委員会で証言を行ったからです。ナレルのこともあって、ヴィクトリア州の首相が介入しました。そしてその結果、ナレルは実のお父さんに会えたのですが、その 3 カ月後に残念ながら亡くなってしまいました。

## 出生者に関する調査研究

私は医学研究者であり、研究室で働いていたので、2011 年、研究哲学の博士号を取得することにしました。それで提供精子、卵子で生まれてきた人たちの研究成果が少ないことに驚きました。わずかに質的研究(qualitative research)の成果はありましたが、量的な研究（quantitative research filed）の報告はほとんどありませんでした。南オーストラリア州やその他の州、あるいは連邦政府の提供型医療での出生者やその他の児童福祉に関する法律では、児童の福祉が最優先事項であるとしばしば述べられています。しかし私たちの福祉を数量的に大規模に調査をした人がいなくて、私たち出生者の福祉が最優先事項として扱われているかどうかをどのように知ることができるのでしょうか。そこで、私は出生者の結果について定量的な調査を自分でしてみようと思いました。

## 2014 年 出生証明書の記載変更を求めて

2014 年、出生証明書について異議を申し立てました。もともと、私の生物学的な父親は出生証明書には書かれていないわけです。つまりその他のオーストラリアの出生者についても生物学的な父親が載っていないわけです。それで正確な出生の記録が欲しいと記載変更を求めました。そのときに私の生物学的父親は分かっていますから、父親欄は空欄であるべきであると。牛や羊のほうは私よりもはっきりとした証明書があるわけです。本当に私たちは物扱いされていると思いました。3 回、私も法廷に出廷しました。証拠を提出しまして、出生証明書の父親の欄に書いてある人は私の生物学的父親ではないと説明いたしました。州の検事総長事務局は、私の異議申し立てに疑念を持ちました。3 人もの弁護士を付けて私の言い分が通らないようにしました。

南オーストラリア州では、基本的には、男性がかかわって生まれてきた子どもから、その男性の子として認知を求められれば、それを否認できないということになっています。それにもかかわらず、2015 年にくだされた判決では、精子提供で生まれた人は、出生証明書に生物学的な父親の名前を入れることを求めてもそれは認められない、つまり 2 級市民で、他の子どもと同じ権利が与えられていないという扱いでした。

### オーストラリアで AID 出生者の会議を開催

2015 年、オーストラリアで提供精子で生まれた人たちの会議を行いました。これは、出生者が同じ部屋に集まった世界最大の会議だったと思います。47 人が集まりまして、講演では、出生者が自分の話をしたり、オーストラリアの各州や世界中の出生者の権利に関する状況について報告したり、DNA 検査に関して情報交換をしました。今、多くの当事者は DNA 検査を行うことで、生物学的な親を見つける人が出てきています。また、アドボカシーグループとして活動したほうが個人よりもいいのではないかと、また人権にかかわる裁判官等から提示されたものの他に、アドボカシーをするためのどのようなサポートグループになればいいのか等、政治家からもアドバイスをもらって、より組織的になり、勢力的に力を合わせてアドボカシー活動を行うようになりました。

2016 も南オーストラリア州の出生者が集団でロビー活動を行って法制度を要求しました。このときにはもっと多くの政治家から反応がありました。たった 1 人の議員ではなく、多くの政治家が耳を傾けてくれました。なぜかと言いますと、1 人で訴えるのではなく、私たちが集団で声を上げたからです。また、先の会議に参加をしてくれた政治家もサポートしてくれました。そこにソニア・アラン教授がいました。アラン教授は、生殖技術と第三者のかかわる生殖医療の領域を専門とする法学者で、アラン教授が私たちをレビュー（調査）してくれました。それによって、ヴィクトリア州と同じように、出生者の権利を認めて、ドナー情報について遡及的なアクセスを可能とすることが提言されました。

南オーストラリア州政府もこれを施行すると合意をしたのですが、直後に選挙があり、政権が交代してしまい、その政権はこの提言にコミットすることができませんでした。しかし、一部の変更は実現することができました。議員立法として代理出産、代理懐胎の法案ともに一部、変更されました。

### ドナーやドナーの家族と会う

2018 年、ある意味での親類の集まりがありました。私にはドナー番号という手掛かりがありまして、ありとあらゆる DNA 検査をしていたので、DNA 検査で叔父に当たるのではないかとという男性が見つかったのです。そしてその男性と DNA 鑑定をして、その人が叔父であることが判明しました。叔父の家族が叔父の兄弟に連絡をしてくれたところ、その兄弟が精子提供をしていたことがわかりました。彼はクイーンズランド州に住んでいたのですが南オーストラリア州に移住して、クリニックからお金をもらって提供したそうです。彼は私だけでなく、彼の孫に当たる私の子どもにも会ってくれるという話になりました。それで、飛行機でクイーンズランドまで行って、みんなで会おうということになったのです。

2018年、自分と似ている人たちのグループ（血のつながった親戚）を見つけました。見た目とか、振る舞いが似ているんです。この写真に私の妻と子どもも写っていますが、私の叔父、叔母、いとこが写ってます。ところが残念ながら、この集まりの2日前に生物学的父はやはり会わないことになりました。家族がそこまで話をしていなかったのです。私は全部、家族経由でやり取りしていて、実の父とは直接話したわけではありませんでした。それから1年半、突然、実の父から電話が来まして、ようやく会う気持ちになったと言ってくれたので。もう一回、クイーンズランドまで行きましてようやく会うことができました。めちゃくちゃ似ていました。性格まで似ていまして、今でもしょっちゅう、連絡を取っています。

### 2019年国連子ども権利条約30周年記念の会議にて

2019年、世界中から私を含めた出生者と、代理出産で生まれた人たち16人がスイス、ジュネーブの国連本部に集まりました。これは国連、子どもの権利条約30周年の会議ででした。私たちはバイオテクノロジーの時代における子どもの権利に関して発表しまして、スタンディングオベーションで受け入れてもらいました。私はその場で、国連の皆さんの目の前で出生証明書を破り捨てました。そして私たちはこの会議を総括するものとして、国際法を作ってもらいたいと言い、その場合に出生者としてその国際法の中に入れて欲しい内容を5つあげました。それが、こちらのスライドにあるものです。今、全部を紹介するのは、時間的にも限りがありますので詳細は説明いたしません。いずれもオンラインで検索できますし、よろしければ私に連絡をしてくだされば情報をお送りいたします。

#### \* 編集者より

詳細は <https://www.donorkinderen.com/united-nations-2019> からみることができます。

参考までに仙波が該当のスライド（スライド17）を翻訳しました。

- 1) 配偶子提供で生まれた子どもや代理懐胎で生まれた子どもは、いつ懐胎し、生まれたかに関係なく、自分のアイデンティティと出自に関する情報にアクセスし、生物学的家族、社会的家族、産みの親との関係を維持する権利を確保する。
- 2) 子どもの受胎に関与したすべての当事者の包括的かつ完全な記録が、将来の世代のために永久的に国家によって保持されることを確保する。
- 3) 提供配偶子で生まれた子どもや代理懐胎で生まれた子どものすべての権利を即座に、そして長期的に与えることを、完全かつ効果的に尊重し、促進する。
- 4) 子どもの最善の利益が、関連するすべての法律、方針、慣行、および司法および行政上の決定において最も重要な考慮事項であることを確認する。これには、ケースバイケースで受胎前の最善の利益の評価が求められる。
- 5) 配偶子、子ども、および代理母のあらゆる形態の商業化を禁止する。これには、人身売買や配偶子の販売が含まれているが、それ以外の形態も含む。

## 南オーストラリア州法改正案 2021 年

2021 年、現在、南オーストラリア州に AID に関して法改正案が出ています。今、パブリックコメントを受け付けています。この改正ができればようやく登録機関ができるということで遡及的にドナーを特定ができる情報にもアクセスができるようになります。匿名のままとするという昔の契約の内容をも覆すことができるようになるのです。もし、これが実現すれば、南オーストラリア州が世界で 2 カ所目のこうした法律を持つところになります。2021 年 2 月までは運用開始になるかと思いましたが、新型コロナの影響があり、若干、遅れてはいますが、それでも年内には運用開始を期待しています。この改定案では、出生証明書の変更も可能としており、提供者の DNA 検査によって出生証明書を変えることも可能となります。そういうことで私の出生証明書も正しく書き換えられる可能性があります。

## 博士論文研究からわかったこと

私の博士論文の研究も終わりました。博士論文の研究結果で分かったのは、提供配偶子で生まれる赤ちゃんは、低体重あるいは未熟児で生まれるリスクが高く、先天性の疾患を持っている可能性が高いことが分かりました。しかも、精子に比べると卵子、胚のほうがそのリスクが高いことが分かりました。このような出生者については、成人後も心身にさまざまな問題を抱えることが多いことも分かりました。これは出産時の問題にも関連があります。子癇前症とか妊娠高血圧症候群とか妊娠時疾患（developmental origins of health and disease phenomenon）といわれているもので、例えば、低体重とか未熟児で生まれた人で、出産のときに問題があった人のほうが成人してから心身の健康にリスクが及ぼす可能性が高いのです。このような私の博士論文の結果から、提供精子で生まれてきた人の福利厚生を、オーストラリア連邦政府と州政府は最優先してこなかったということが分かりました。

## まとめとして

まとめにはいます。私がこの旅を通してわかったことは以下のようなことです。法改正を実現するのは非常に痛みを伴う長いプロセスであるということ。また不妊治療クリニック、あるいは医師が全部、反対をしてくれましたし、私たちに対してひどい発言をメディアはしてくれました。そして、今日は触れませんでしたけれども、数えられないほどの取材を受けてきました。新聞、テレビ、ラジオで取材を受けなければいけないのです。世論を形成するために、そもそも注目をしてもらうために大量の取材を受けなければなりません。また、何もよりも重要なのは、心と心で政治家と地域がつながることです。どれだけつらいのか、分かってもらう必要があるからです。また、1 人で動くのではなく、集団で声を上げるほうがアドボカシーの効果があることを学びました。また、専門家、あるいは、専門知識がある人、例えば、弁護士、科学者、倫理学者にサポートいただくことは大事です。養子縁組関係者と相談することも大事です。また、政治家などがサポートしてくれることが重要です。それによって変化を起こすことができます。また、法律、倫理、科学に基づいた論理的な議論の主張が大事であることが分かりました。

ご清聴ありがとうございました。

## Presentation

Hello. My name is Damian Adams and I'm here to talk to you today about my own personal journey for creating legislative change here in Australia and South Australia. But first, a little bit of background about myself. I was conceived by donor sperm in 1973 at a public hospital here in South Australia, which would become the first sperm bank in Australia in 1972. I grew up always knowing I was donor conceived, which was highly unusual for the time as most parents were told to keep it a secret. However, my parents realized the value of telling the truth and that my welfare would be better served by knowing my origins.

Growing up being donor conceived wasn't really an issue for myself as I was too busy being a child and going to school. I really wasn't that interested in seeking information on the donor, my biological father. In regards to information here in Australia, most people conceived after 2004 have access to identifying information on their biological parents with the exception of Victoria, which gained access a little bit prior to that.

For everybody else like me conceived prior to 2004, we do not have access to identifying information. In South Australia, legislation allowed the access to non-identifying information, which I decided to seek at the age of 15, because I was having difficulty with my identity construction. It was quite a traumatic time for me. We approached the clinic, who said that the records were destroyed. Then five years later at the age of 20, I needed some health information on the donor because I had doctors who could not identify and diagnose an illness that I had at the time. We went back to the clinic and the story from the clinic had changed.

Now, they said that the records were lost, that they weren't destroyed. This raised some red flags for us. We then submitted, what's called a Freedom of Information request. Here in Australia these are a statutory binding requests simply because of the fact that these records were my mother's treatment records and legally they belonged to her, and therefore she could request them. Now the clinic, funnily enough managed to actually find those records and they did actually exist, showing that they lied to us. Many other donor-conceived people here in Australia have found the same thing that they have been lied to by the clinics and they've found this out when they've submitted a Freedom of Information request.

However, even though we now had this information, we didn't have identifying or non-identifying information and the clinic would not match the donor code to any donor records for us. Fast forward to 2003 and I started a family of my own. I had grown up always supporting donor conception and anonymity, even though I'd suffered with my own identity construction and other health issues. But this support was due to something known as existential debt. This is where we think that the reason for our existence, must be supported, because otherwise we



wouldn't exist. However, there are many different arguments against having to feel grateful for the method of our conception, which is a topic for debate another time.

It was the birth of my daughter, which changed my perspective 180 degrees. I got to see myself in my daughter and the connection that we had, which was something that was missing in my own life that I didn't have. This was the mirror of myself that would be seen in my biological father. It really became a light bulb moment or an epiphany.

From there, even though I couldn't get access to information for myself, which would assist my own personal journey, even if I couldn't get that, I felt that if I could do something to prevent other donor conceived people from going through the same trauma and situation that I had, that I would do that. I then undertook doing some advocacy. The following presentation I'm doing for the rest of today will include just a snapshot of some of the advocacy we've done here in Australia with the inquiries and legal reviews. It is not exhaustive, but it is just to give you a little bit of a picture of what has gone on.

After the birth of my daughter, I started campaigning for donor conceived people's rights. That included writing to the Australian Human Rights Commissioner, the Federal Minister for Health and Aging, the South Australian Premier, two health ministers here in South Australia, as well as every single South Australian politician in both the upper and the lower house of parliament.

The only politician that really responded to my request was the Honorable Bob Such, who took my case to South Australian Parliament. From which we achieved some amendments in 2009, that saw the introduction of a voluntary registry in South Australian Law. But unfortunately, there was a caveat in there and a clause in which it stated that the minister may keep a register rather than the minister must keep a register. Subsequently because of that, we still don't have a register to this day.

In the following year, a group of donor conceived people including myself and members of the donor conception support group of Australia, including recipient parents submitted a petition to federal parliament. This leads to the establishment of the Senate inquiry into donor conception practices here in Australia.

As a result of that inquiry, there were a bunch of recommendations which included to have nationally consistent legislation, because here in Australia donor conception is governed by state law and each state has different legislation. It suggested that we should have a register for donor conceived people, as well as the protection and welfare of donor conceived people. It suggested and recommended that we maintain the prohibition of anonymity as well as include donor limits.

It was a total of over 30 other recommendations. However, because health law is a part of state

jurisdiction, this inquiry achieved very little. In the following year in the state of Victoria, they held a state based inquiry. The chair of this inquiry admitted afterwards, that they actually went in believing that they would uphold the status quo and not make any changes to the access of identifying information. However, they listened to the stories of the donor conceived people. They listened to our pain, our trauma, our suffering, and when we cried, they cried.

The chair of this inquiry also stated after the inquiry that the committee was convinced that this right referring to the right to identifying information on the donor must be given precedence over the wishes of those donors who would like to remain anonymous. They recommended retrospective access be given to identifying information which would become the world's first. However, changes to law always take time and it wouldn't become implemented until 2015 and be called Narelle's Law after donor conceived person, Narelle Grech, who appeared before this inquiry. Narelle had terminal bowel cancer. Because of her situation, the Victorian premier intervened and Narelle got to meet her biological father, but sadly three months later she passed away.

In the same year, I decided to undertake a doctor of philosophy by research because I'm a medical research scientist, who has worked in the labs and was surprised by the lack of research that had been conducted into the outcomes for donor conceived people. Some of this had been qualitative research, but there had been very little in the quantitative field. Here in South Australia and as well as in other states and Australian legislation regarding donor conception and other areas of child welfare, it often states that the welfare of the child is to be paramount. But in regard to donor conception, if no one has investigated our welfare from a quantitative perspective then how do they know whether our welfare is being treated as paramount? I undertook an investigation into the quantitative welfare outcomes of being donor conceived.

Then in 2014, I challenged my birth certificate in a court of law. The man listed on my birth certificate is not my biological father, as it is for any other normally conceived person here in Australia. What I wanted was an accurate record of my birth to remove the man listed and to leave it blank, because I did not know at that time who my biological father was. Furthermore, my dog and other livestock such as cattle and sheep have a more accurate birth record than I do, which is incredibly dehumanizing.

I had three appearances in court representing myself with evidence, which was unequivocal to prove that the man who was listed on my birth certificate was not my biological father. The Attorney General's office was worried about what my challenge would actually represent, sent three lawyers to challenge me in court to make sure that I lost.

I received judgment in 2015 rejecting my application. In effect this basically meant that every

other South Australian can rebut paternity, which means that they can all challenge paternity, except donor conceived people. Meaning that donor conceived people here are essentially second-class citizens.

Also in 2015, we held a conference in Australia for donor conceived people. At the time we believed this was perhaps the largest gathering of DC adults in the world in a room, with a total of 47. We had presentations including personal stories from donor conceived people, information on the rights of donor conceived people in Australian states and around the world, and information on DNA testing, which is something that many donor-conceived people are now doing and being able to find their biological families through these methods.

We had information on advocacy as a group rather than as an individual, advice from politicians on how to advocate, as well as presentations from a human rights judge. Consequently, we now have groups of donor-conceived people who now advocate together in a much more organized and strategic fashion.

In 2016, a group of South Australian donor conceived people lobbied the politicians for a change in law. We now had a greater response from more politicians. We had many responses rather than a single one previously, partly because there is power of being able to advocate as a group versus one person. We also had the politician that attended the Donor Conception Conference who championed this cause. Subsequently there was a review of the legislation conducted by Professor Sonia Allan, who is a legal academic specializing in reproductive technology and donor conception.

This review recommended retrospective access to identifying information being given retrospectively to donor conceived people, which would be the same as occurred in Victoria. The South Australian government agreed to implement these recommendations. But unfortunately, an election occurred shortly after, we had a change in government and the new government did not commit to these recommendations. However, we were able to bring in some of these changes later through a private members bill, which was put in on the back of a surrogacy bill.

Then in 2018, I had somewhat of a family reunion. I had clues on who my father is with the donor code and I'd conducted numerous different DNA tests. Then we had a match with somebody who may possibly be an uncle and who agreed to take a DNA test for me. This test confirmed that he was indeed my uncle. His family then contacted all of the brothers, with one confirming that he was indeed a donor. He had traveled from Queensland, where they all lived, to South Australia to be a donor, which was paid for by the clinics. He agreed to meet me and my children, which are his grandchildren at a family reunion in Queensland. We flew across the country to meet them all.

In 2018, I finally found a group of people that were similar to me, in looks and behaviors. In this image here, you will see a picture of my wife and my children, and my uncles, aunties, and a cousin. However, sadly, two days before the reunion, my father decided not to meet me. We hadn't spoken up until that time and all communications had occurred through his family.

However, 18 months later and out of the blue, I received a phone call from my father and he was now ready to meet me. I flew back to Queensland where I finally met him. We have extremely similar looks and personality traits, and we are still in constant contact to this day.

In 2019, a group of 16 donor conceived people, including myself and a surrogacy conceived person from around the world converged on the United Nations in Geneva, Switzerland for the Thirtieth Anniversary of the United Nations Convention on the Rights of the Child.

We did a presentation on the topic of children's rights in the age of biotechnology, which focused on children who were conceived from reproductive technologies. We had received a standing ovation, and at this conference I ripped up my own birth certificate in front of the United Nations. The outcome of this conference for us was that we put together five recommendations for donor conception to occur, which I have listed here.

I don't have time to go through these with you today due to time constraints. But if you would like to see these, they are freely available online or you are free to contact me and I will send them to you.

Currently in 2021, we have a South Australian Amendment Bill for Donor Conception, which is currently under public consultation and review. What this amendment bill would mean is that we would finally not only have this donor conception register, but it would also include retrospective access to identifying information, which would overturn previous anonymity agreements, making South Australia the second jurisdiction to do so. The register should be and must be operational by the end of 2021. However, sadly COVID has impacted that a little bit and it is delayed, but we are still hoping that it may be implemented by the end of this year. Without the amendment bill, the register will only be prospective rather than retrospective. This amendment bill also proposed to include the ability to change a birth certificate with a donor's consent and also a DNA test, so I may eventually be able to have a truthful birth certificate.

I also finished my Ph.D. this year from which I found that donor conceived babies are at greater risk of being born of low birth weight, preterm delivery and of having increased incidences of birth defects, which is dependent on whether they were born from donor sperm or donor eggs and embryos such that the risk for those people conceived with donor eggs and embryos is greater than those conceived with donor sperm.

We also found that donor conceived adults also were more likely to suffer from a range of

physical and mental health outcomes. We also found that this was associated with maternal complications of pregnancy, such as preeclampsia and pregnancy-induced hypertension. This all falls under what is known as the Developmental Origins of Health and Disease (DOHaD) phenomenon, which stipulates that those people who were born of poorer outcomes such as low birth weight or preterm delivery are more likely to go on and suffer adverse outcomes in their health later on in life.

From this, we were able to conclude that the welfare of donor conceived people indeed had not been treated as paramount in this state or country.

In conclusion, what I've found along this journey is that getting legislative change is a very long and painful process. We have had fertility clinics and clinicians oppose us every step of the way and have even made derogatory comments about us in the media. Of which I haven't mentioned along this journey is the countless newspaper, TV, and radio interviews that donor conceived people have undertaken, which has been needed to frame public debate and draw our attention to the issues.

What we've also found is that it's vitally important to connect emotionally with the politicians and the community as they need to understand and connect with our pain and trauma. We've also found that getting a group together is a far more powerful way of achieving advocacy and that also having people with a professional status and knowledge helps such as lawyers, scientists, and ethicists. Also it has also been important to link to other sociological phenomenon, such as adoption. We've also found it's been vitally important to have a champion, such as a politician, to help drive this change and to have a logical argument that is based on law, ethics and science.

Thank you for your time.

## Presentation Slides



### Conception By Donor - 1973

Conceived at a public hospital clinic – the first sperm bank in Australia opened 1972.

Grew up always knowing I was donor conceived (unusual).

Wasn't an issue as I was too busy being a child.



## The Search For Information

In South Australia, legislation allowed the access to non-identifying information at age 15 (1989), but not identifying info (conceived post 2004 = yes).

Clinic said the records were destroyed.

Age 20 needed health information on the donor.

The narrative from clinic changed – records were just lost, not destroyed.

Freedom Of Information request (statutory binding request) showed they lied  
– records existed (many other DCP been lied to → FOI).

Clinic would not match the donor code to any donor records.

## Family Of My Own - 2003

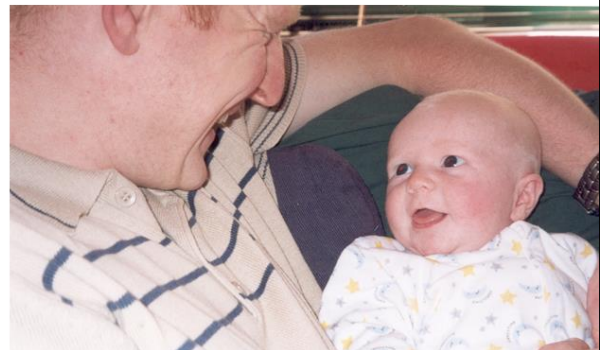
Growing up I supported DC and anonymity

- even though my own identity construction was adversely affected,
- existential debt.

Birth of my daughter changed my perspective 180°

Saw myself in my daughter but did not have my father to see myself in.

Epiphany



## Early Advocacy for Legislative Change

Following presentation of some advocacy is not exhaustive of all Australian inquiries and legal reviews but presents a snapshot (picture)

Shortly after the birth of my daughter I started campaigning for DC rights:

- Australian Human Rights Commissioner,
- Federal Minister for Health and Aging,
- South Australian Premier,
- South Australian Ministers for Health (x2),
- Every single South Australian politician in both upper and lower house.

Hon Bob Such MP took my case to SA parliament achieving amendments in 2009 which saw the introduction of a voluntary register in SA law – but.....

## Federal Senate Inquiry - 2010

22 Feb 2010, DCSG submitted a petition to Federal Parliament  
- established the Senate Inquiry into Donor Conception Practices in Aus.

Recommended:

- nationally consistent legislation,
- a register,
- protection of welfare of DCP,
- maintain prohibition of anonymity,
- donor limits,
- + over 30 other recommendations.

Health law = state jurisdiction  
∴ inquiry achieved little.





## Victorian Parliamentary Inquiry - 2011

Chair admitted post-inquiry that they went in believing that they would uphold the status quo – not make any changes.

They listened to the donor-conceived. When we cried. They cried.

"The committee is convinced that this right must be given precedence, even over the wishes of those donors who would like to remain anonymous."  
→ recommended retrospective access to identifying information (world 1<sup>st</sup>)

Changes to the law would take time – Narelle's Law (2015).

In the mean-time the Victorian Premier intervened.

Narelle died 3 months after meeting her father.



## **Doctor of Philosophy – by Research - 2011**

As a medical research scientist working in laboratories I was surprised by the lack of research into the outcomes for DCP.

Some qualitative research but very little quantitative.

Legislation states that the welfare of the child is paramount but.....  
no one had investigated their welfare from a quantitative perspective.

Investigation into quantitative welfare outcomes of DCP.

## **Birth Certificate Challenge - 2014**

The man listed on my birth certificate is not my biological father.

Wanted an accurate birth record – remove the man listed and leave it blank.

My dog has more accurate birth record – dehumanizing.

3 appearances in court with evidence proving the man listed is not my father.

Attorney general's office challenged my application  
→ 3 lawyers to make sure I lost.

Judgment received 2015 – every other South Australian can rebut paternity except  
DCP = 2<sup>nd</sup> class citizens.

## **National Donor Conception Conference - 2015**

Largest gathering of DC adults in world at the time (47)

Presentations included:

- Personal stories from DCP,
- Current rights for DCP in Australian states and around the world,
- DNA testing – now so many have found their family,
- advocacy as a group rather than individually,
- advice from a politician on how to advocate,
- human rights judge.

Groups of DCP starting advocating together - more organised and strategic.

## **South Australian Legislative Review - 2016**

Group of South Australian DCP lobbied politicians for a change in law,

- had greater response from more politicians (many versus one),
- politician that attended DCP conference championed the cause,
- review conducted by Prof Sonia Allan (legal academic).

Review recommended retrospective access to information (same as Victoria).

Government agreed to implement the recommendations:

but.....election.....change in government  
→ new government did not commit.

Changes brought in through private members bill on back of surrogacy bill (2018).

## Family Reunion - 2018

Clues on who my father is:

- donor code,
- conducted numerous different DNA tests
- contacted a possible uncle who took DNA test – confirmed uncle
- they contacted a brother who confirmed he was a donor (Qld – SA).

He agreed to meet me and my kids (his grandchildren) at a family reunion in Queensland (across country).

## Family Reunion - 2018

I had finally found people that were similar to me.



2 days before the reunion he decided not to meet me. We had not spoken.

## The Apple Does Not Fall Far From The Tree

18 months later I received a phone call from my father.

He was now ready to meet me.

Fly back to Queensland.



## United Nations – 30<sup>th</sup> Anniversary UNCRC - 2019

UN – Geneva, Switzerland – 16 DCP and a surrogacy conceived person from around the world

→ Standing ovation – ripped up my birth certificate.

- 1) Ensure the right of donor-conceived and surrogate-born children to access information about their identity and origins regardless of when these children were conceived and born, and to preserve relations with their biological, social and gestational families.
- 2) Ensure that comprehensive and complete records of all parties involved in the conception of the child be held by the State in perpetuity for future generations.
- 3) Respect and promote the full and effective enjoyment of all the rights of donor-conceived and surrogate-born children in both the immediate and longer terms.
- 4) Ensure that the best interests of the child be the paramount consideration in all relevant laws, policies and practices and in any judicial and administrative decisions. This requires a best interests assessment pre-conception on a case-by-case basis.
- 5) Prohibit all forms of commercialisation of gametes, children and surrogates including, but not limited to, the sale and trafficking in persons and gametes.

## South Australian Amendment Bill - 2021

Currently under public consultation and review.

Donor conception register – retrospective access.

→ overturning previous anonymity agreements (2<sup>nd</sup> jurisdiction),

→ must be operational by end of 2021.

Also proposed to include the ability to change BC with donor's consent and DNA test.

## PhD – Completed Journey

DC neonates at greater risk of low birth weight, preterm delivery, birth defects (sperm v egg/embryo).

DC adults reported increased:

- diagnosis of diabetes type 1, thyroid disease, acute bronchitis, environmental allergies, sleep apnoea, attention deficit disorder, autism and depressive disorder,
- experiences of seeing a mental health professional, identity formation problems, learning difficulties, panic attacks, recurrent nightmares, alcohol/drug dependency, and eating disorders.

Associated with maternal complications (preeclampsia & PIH) → DOHaD.

Subsequently, welfare of DCP has not been treated as paramount.

## Conclusion

Getting legislative change is a long and painful process.

- fertility clinics and clinicians have opposed every step.

Didn't mention the countless newspaper, TV and radio interviews needed to frame public debate and draw attention to the issue.

Need to connect emotionally with politicians and the community  
– they need to understand and connect with the pain.

Getting a group together is far more powerful.

Having people with professional status and knowledge helps,  
lawyers, scientists, ethicists etc.

Need a champion (politician) to help drive change.

Have a logical argument based on law, ethics and science.

## Thankyou

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オンライン国際フォーラム  
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出自を知ることがなぜ重要なのか Why Is The Right to Know Important?  
提供精子で生まれた人たちの経験と思い The Experiences and Thoughts of Donor-Conceived People

