

# A child as a live organ donor?

## A glimpse into New Zealand's legislation

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Organ transplant is a surgical procedure that aims to implant healthy organs from live or deceased donors into patients with organ dysfunction or failure. In New Zealand, the first kidney transplant was successfully done in 1965 at Auckland City Hospital and currently an average of 57 kidney transplant operations involving live donors were performed each year.<sup>1</sup> At the moment, the minimum age for live kidney donation is 18 years old.<sup>2</sup> But if the needs arise, is this country constitutionally ready to deal with live organ donation from someone younger? Does New Zealand have adequate legal protection over both the 'child' donor and recipient? This article attempts to answer this by discussing the medico-legal issues illustrated in two such cases in America, *Hart v Brown* and *Curran v Bosze*.

### CASE 1: HART V BROWN (1972)<sup>3</sup>

In *Hart v Brown*, 7 year-old Kathleen Hart suffered a life-threatening kidney disease. The treatment options then were either lifelong dialysis or a kidney transplant in which the latter, according to physicians, could provide better outcome. The child's parents offered their kidneys for the transplant but it was Margaret, her identical twin sister, who would be the most compatible donor.

However, the transplant surgeons refused to perform the operation and the hospital refused the use of its facilities without the court's consent to the transplant. The twin's parents then sought a declaratory judgement to permit them to consent to a kidney transplant from one daughter to her twin sister.

The court took into account the testimony from a psychiatrist, who testified that the donor had strong identification to her twin sister, and also a testimony from a clergyman, who stated that the decision of the parents and the child donor was morally and ethically sound. Also, the donor's court-appointed guardians ad litem gave their consent to the procedure.

The court then granted the parents' request to consent to a kidney transplant from Margaret to Kathleen. In this case, the donation was viewed as in the child donor's best interest. If the expected successful results are achieved, the donor would also greatly benefit emotionally because she was believed to be better off in a family that was happy than in a family that was distressed. Furthermore, if the recipient were to die from her illness, then that was viewed as a very great loss to the donor instead because of

their close relationship.

Gaining consent from the child donor was also an issue. In this case however, the court allowed the parents to consent to the transplant instead of their child after thorough investigation of their motivation and reasoning through the participation of a clergyman, a psychiatrist, the child donor's guardian ad litem and the recipient's guardian ad litem.

### CASE 2: CURRAN V BOSZE (1990)<sup>4</sup>

This case involved a father of twins requesting the court to allow the twins to undergo a compatibility blood test. The father also requested the court to allow the twins to undergo a bone marrow transplant for the twin's half-brother, Jean Pierre Bosze who is suffering from a life-threatening acute undifferentiated leukaemia. Jean Pierre and the twins are the children of Mr Bosze but they have different mothers. Ms Curran is the mother of the 3-and-a-half year old twins and she refused consent to both the blood test and the bone marrow transplant. She believed that it was not in the best interest of her children to do so despite the blood test being minimally invasive.

In desperation, Mr Bosze filed an emergency petition. Mr Bosze and the guardian ad litem for Jean Pierre argued that the doctrine of substituted judgement should be applied in this case, which requires a surrogate decision maker to attempt to establish what decision the patient would make if the patient were competent to do so. The application of the doctrine was objected by Ms Curran and the guardian ad litem for the twins because they believe that it was impossible to clearly and convincingly produce evidence whether or not the twins would consent to the operation should the twins have the competency of an adult.

The court was sympathetic with Jean Pierre but since it could not be established that both procedures would be in the best interest of the twins and also failure of consent from the mother, the emergency petition by Mr. Bosze was rejected.

Both cases were brought to the attention of the courts because they were minors who were deemed to not be as competent as adults in making judgements about risk taking and avoiding self-harm. Organ transplant is an invasive operation which carries some risks to the donor, such as risks of general anaesthesia or excessive bleeding, and does not provide any medical benefit aside from possible psychological gain.

Nevertheless, the case reports did not highlight the donor children's view of the situation perhaps because they were too young. However, suppose the donor children were a bit older, have their own opinion of what they would do in the situation, would they have the right to voice out their own opinion? And would their opinions affect the verdict?

## CHILDREN'S RIGHTS: NATIONALLY AND GLOBALLY

There are a number of legislations that aim to protect the welfare of children in New Zealand namely the Children's Commissioner Act 2003, the Children, Young Persons and Their Families Act 1989, the Guardianship Act 1968, the Education Act 1989 and the New Zealand Bill of Rights Act 1990 among others.<sup>6</sup>

Globally, The United Nations Convention on the Rights of the Child (UNROC) is an international human rights treaty that sets out a child's civil, political, economic, social, health and cultural rights.<sup>7</sup> It is a legally-binding Convention as nations that ratified it are bound to it by international law. New Zealand had ratified the Convention in 1993 with some reservations.

In New Zealand, the Children's Commissioner and his or her staff, under the Children's Commissioner Act 2003, are working with the Government to implement UNROC. Section 3(c) of the Act states that one of the purposes of the Act is "to confer additional functions and powers on the Commissioner to give better effect in New Zealand to the United Nations Convention on the Rights of the Child".<sup>8</sup>

The UNROC has a total of 54 Articles. Article 1 of the Convention defines a child as "Every human being below the age of eighteen years unless under the law applicable to the child, majority is attained earlier".<sup>7</sup> Therefore in adopting the Convention, the international community recognised that people under 18 years of age often need special protection and care that adults do not. This article will look into some of the relevant articles in the Convention regarding the care and protection of a child in becoming an organ donor.

Article 3(1) of the Convention recognises the need to put a child's best interest as the topmost priority:

### Article 3(1)

"In all actions concerning children ... the best interests of the child shall be a primary consideration."

This means that in every proposed case of organ donation by children, a thorough check on the motivation and reasoning behind the use of a child donor needs to be undertaken. Only after careful consideration and successful identification of the child's best interest should the transplant be approved. This is especially important to ensure that the child is not subjected to exploitation, which is also set out in Article 36. As a general rule, children should always be protected from any activity that takes advantage of them or could harm their welfare and development.<sup>7</sup>

### Article 36

"States Parties shall protect the child against all other forms of exploitation prejudicial to any aspects of the child's welfare."

In making the decision whether or not to donate organs, a child often relies on parents to help them and this is respected by the Convention in Article 5 which states:<sup>7</sup>

### Article 5

"States Parties shall respect the responsibilities, rights and duties of parents or, where applicable, the members of the extended family or community as provided for by local custom, legal guardians or other persons legally responsible for the child, to provide, in a manner consistent with the evolving capacities of the child, appropriate direction and guidance in the exercise by the child of the rights recognised in the present Convention."

On the other hand, if the child has his or her own opinion regarding any aspect of the proposed organ donation, Article 12(1) states that the child has the rights to let her parents and the transplant team know of that opinion, and that the child's opinion should be taken into consideration in any decision-making, though it still depends on the age and maturity of the child. Article 12(2) further stresses the importance of listening to the child's view by ensuring that the child should be provided the chance to be heard.<sup>7</sup>

### Article 12

(1) "States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child."

(2) "For this purpose, the child shall in particular be provided the opportunity to be heard in any judicial and administrative proceedings affecting the child..."

Moreover, the Children, Young Persons and Their Families Act 1989 offers care and protection to children that may be considered as similar to the UNROC but are more representative of the New Zealand culture particularly Maori's strong family culture. For example, Section 5 of the Act states that family members should take part in making decisions that could affect the child which is quite similar to Article 5 of the Convention; parents could provide appropriate direction and guidance to the child in making a decision.<sup>9</sup>

### Section 5: Principles to be applied in exercise of powers conferred by this Act

Subject to section 6, any court which, or person who, exercises any power conferred by or under this Act shall be guided by the following principles:

(a) the principle that, wherever possible, a child's or young person's family, whanau, hapu, iwi, and family group should participate in the making of decisions affecting that child or young person, and accordingly that, wherever possible, regard should be had to the views of that family, whanau, hapu, iwi, and family group:

(b) the principle that, wherever possible, the relationship between a child or young person and his or her family, whanau, hapu, iwi, and family group should be maintained and strengthened.

Dealing directly with the issue of organ transplant and donation is the Human Tissue Act 2008, as the Act includes "whole human organs" (Section 7 (4) (b)) in its definition of 'human tissue'. In addition, the interpretation of the word 'use' in Section 6(c) includes the use of that tissue in carrying out a health-care procedure (for example, the administration or transplantation of that tissue).<sup>10</sup> Nevertheless, there is no specific section in the Act that outlines the regulations regarding whole organ donation, especially the issue of minimum age and ability to consent.

However, it is interesting to note that Section 26 of the Human Tissue Act 2008 states that a person who is 16 years old or older is entitled to be assumed as capable.<sup>10</sup> Does this mean that a child above the age of 16 could be assumed as capable of consenting to organ donation? This could be the case since Section 36 of the Care of Children Act 2004 appears to be in agreement with it.<sup>11</sup>

### Section 36: Consent to procedures generally

A consent, or refusal to consent, to any of the following, if given by a child of or over the age of 16 years, has effect as if the child were of full age:

(a) Any donation of blood by the child:

(b) Any medical, surgical, or dental treatment or procedure (including a blood transfusion, which, in this section, has the meaning given to it by section 37(1)) to be carried out on the child for the child's benefit by a person professionally qualified to carry it out.

## ETHICAL ISSUES

### Informed Consent:

Consent may be defined as 'granting someone the permission to do something that they otherwise would not have the rights to do so'.<sup>12</sup> Perhaps a more holistic approach to consent, particularly in the medical setting, is informed consent which would include the need for the consent to be made after knowing what action or treatment the consent is given to, having access to related information, being assisted in the process of understanding, knowing the potential danger and risks of the action and having enough time to decide. The consent must also be made voluntarily, without coercion or pressure.<sup>13</sup>

It is acknowledged that a child's state of mental development is not the same as adults. This puts children in a vulnerable state because they have a much limited capability to understand the treatment procedures and to weigh its potential risks.<sup>13</sup> Hence, providing informed consent to a child is therefore much more complicated than to an adult. However, as a child gets older and more mature, the capability of understanding complex information increases and so do their capability to weigh risks and options. The child should be encouraged to give his or her opinion and have that opinion respected, as stated in Article 12 of the UNROC.<sup>7</sup> A child is said to be Gillick competent and can give consent provided that he or she has 'sufficient understanding and intelligence to enable to understand fully what is proposed'.<sup>13</sup>

### Best Interest:

It is important to remember that the decisions made during childhood may have significant impact on the child's present and future. Therefore, it is very important to make sure that the child is treated to favour his or her best interests. It requires the decision maker (for example, parents deciding for their child) to consider both the current and future interests of the proposed child organ donor, and then decide the best course of action. In organ donation, physical harm is inflicted upon the child donor in benefit of another person, but to what extent is this permissible?

UNROC did not precisely define what constitutes as 'best interest' of the child although the term is being used many times in the Convention. Granted it is difficult to describe and draw a line as to what is in the best interest of a child. Often it depends on a lot of individual circumstances, such as the age and the level of maturity of the child and the child's environment.

In the Curran case<sup>4</sup>, three critical factors were found necessary by the court to determine the best interest of the child: (1) the consenting parent must have been informed of the risks and the benefits of the procedure; (2) there must have been emotional support available to the child from his or her caretakers; and (3) there must have been an existing, close relationship between the donor and recipient. Given these circumstances, the court found that there was insufficient evidence of close personal relationship between the children and hence compatibility testing and bone marrow donation was not deemed to be in the child donors' best interest.<sup>4</sup>

On the other hand, in Hart v Brown,<sup>3</sup> it was decided that the transplant of kidney from a child to her twin sister was in the donor's best interest. If the transplant operation was not done and the sick twin dies from the disease, the negative psychological impact on the healthy twin is deemed to be

more damaging than the risk of the operation since they both had a close relationship. However, this can be debated.

## CONCLUSION

Organ donation by a child is a complex issue and should be dealt delicately with parents or guardians having the duty to care and protect their children. Hence, in making the decision regarding organ donation, the child should be guided and assisted in the best possible way and the final judgement should always be in the child donor's best interest. New Zealand may be inexperienced in the field of live organ donation by children but it is reassuring to know that some basic legal structures surrounding it are already present.

## DISCLAIMER

This article represents the view of the author only and does not constitute the full analysis of the New Zealand legislations nor their interpretation.

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