Author's response to reviews

**Title:** The Policy Statement of the American Academy of Pediatrics - Children as Hematopoietic Stem Cell Donors - a proposal of amendments for better protection of minors

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**Author's response to reviews:** see over
Dear Editors,

Re: A critique on the Policy Statement of the American Academy of Pediatrics – Children as Hematopoietic Stem Cell Donors – conditions too easy to fulfill

I am truly indebted to the invaluable comments from the reviewer Dr Wendy Rogers. First, I would like to ask your permission to change the title of the manuscript into

**The Policy Statement of the American Academy of Pediatrics – Children as Hematopoietic Stem Cell Donors – a proposal of amendments for better protection of minors**

In light of Dr Roger’s comments, I would like to respond as follows:

1. I note that the authors do cite evidence for their position but Dr Morgan has not specifically commented this on, and the authors have noted that this was not a comprehensive literature review but have not commented on whether or not their claims are contentious.

Response:
I have explicitly mentioned that our claims are not contentious. The following is added:

> It is already well established that the use of haplo-identical transplant is equally safe and effective for advanced lymphoma or leukemia, whereas studies are still underway to evaluate the results with non-malignant diseases like aplastic anemia, lupus and sickle cell diseases. The above literature search by no means suggests that haplo-identical transplant can replace tissue-matched transplant but, given the success of new regimens of transplantation, doctors should look beyond the availability of tissue-matched related donors for certain types of diseases.

[lines 16 - 22, page 9]

2. The grounds for these two conditions are not clearly related to the potential donor’s best interests. It may be more straightforward to talk of the balance of benefits and harms, rather than of best interests per se, or if the language of best interests is retained, then these should be further specified.

Response:
I have added the following:
In case the donor sibling is an incompetent minor, a parent must proceed to assess the best interests of the donor. The assessment of best interests is a balance of the benefits and risks of transplantation for the donor. The procedures need not be risk free but parents should only consent to tissue harvest if the possible benefits for the donor outweigh the potential harm.

[lines 18 – 22, page 4]

It cannot be said that tissue harvest can offer any significant long-term benefits for the donor sibling if other available source of transplant can offer a similar chance of success or if the sick sibling can survive without serious complications even without transplantation.

[lines 16 – 19, page 7]

In short, the only circumstance where tissue harvest would serve the best interests of a minor donor is that without the proposed transplantation taking place, the sick sibling will more likely suffer serious complications or die.

[lines 5 – 8, page 8]

3. To me it seems quite plausible that a donor may feel pride in having been the donor even if there were others who might also have fulfilled this role. This sense of pride is a potential psychological benefit even if it doesn’t materialize for the reasons given by the authors, and therefore may be legitimately considered by the parents when making decisions for incompetent minors.

Response:
I have rewritten the paragraph as follows:

Those who do not agree may argue that a donor sibling may in the future relish and take pride in being a donor and therefore still want to donate even if other donors are available. Parents may legitimately consider this factor when making decisions for incompetent minors. But the remoteness of this benefit should take its edge off from the evaluation. The sense of pride may not materialize if the grown-up donor sibling does not accept the filial or social responsibility to save the recipient sibling, is disinterested in altruistic donation, or does not relish in living in the shadows of the recipient sibling. In any event, it is only for a competent individual to decide whether they want to take the risks in exchange for just the goodwill and the pride of being ‘a donor and a saviour’. For minors, we hold that the benefits of this alone are too remote and small in magnitude to justify the medical risks of life-threatening bodily intrusion.

[line 20, page 7 – line 5, page 8]

4. In the discussion of unsuccessful transplants, there is no mention of guilt or shame that may be felt by a sibling who was not a donor, or potential anger towards parents for not allowing them to be a donor, given the subsequent death of the sibling. Thus
there may be a particular kind of survivor guilt in matched siblings who were not used as donors.

Response:
We do advise using donor sibling if it has a significantly higher chance of success. In other words, transplant from other donors should be used only if it has equal or similar chance of successful transplantation. Therefore, if transplant from other donors (which has equal chance of success) fails, the chance of transplant success would not have been improved even if the donor sibling had been used. As we argued in the article, sadness and a feeling of guilt will almost certainly be present if transplant fails. If using the tissues from donor sibling rather than other unrelated donors would not increase the chance of transplant success, it would not reduce the chance of a feeling of guilt either. I don't want to put this argument in the manuscript as this seems to make the argument very bulky.

5. The suggested new clause 6 for the Policy seems to be an amendment to clause 1 rather than a new point.

Response:
I have made changes accordingly.

In the circumstances, I propose that the following should replace the original first and third criteria in the Policy:

1. If the medical conditions of the recipient permit a search, there is no medically equivalent haplo-identical/histo-compatible adult who is willing and able to donate;

3. The recipient sibling will likely suffer from serious complications or die without transplantation before the donor sibling becomes Gillick competent, [lines 2 – 10 page 10]

Thanks very much. I look forward to the article being accepted soon.

TK CHAN