A woman and her husband have a set of identical twin girls. The couple knows that something is wrong with one of their children because the second child is rushed away. Later the doctor comes in and informs the couple that one of their twins has been born with a variety of health problems and she will at some point in her life need a new kidney. The couple is distressed because they know that this is going to be a difficult process. The sick child manages to stay alive, but she has to take daily dialysis. The doctors inform the couple that their child will need a transplant to stay alive.

The History of Sibling Donors

The doctor informs the couple that the sick child’s identical twin would be the best match. The couple is placed in a difficult situation; they must decide whether they want to have their young healthy child undergo major surgery in order to save her twin sister’s life. The parents weigh their options and realize that although one of them might be a match, the chances of rejections would decrease and fewer complications would be likely if her identical twin was the donor.

Many families are faced with the same decision as the couple; they have one sick child and at least one healthy child who can rescue the family by becoming a donor for their sibling. Children have been serving as donors since the first year of successful
organ donation.¹ The first successful kidney transplant from a living donor to another living person was performed by John P. Merrill, Joseph Murray and John Hartwell. This transplant was performed between identical twins.²

Siblings are particularly well suited to be living donors for each other.³ Sometimes parents are not a good match to be living donors because they either do not have organs that are a good match or they are not in good enough health to be living donors.⁴ Twins are an even better match for a variety of reasons. First, there is a shortage of donors both living and dead.⁵ There are hundreds of children every year who are on the waiting list to have an organ transplant.⁶ Some of these children will die waiting for an organ or tissue transplant that could be taken from a sibling.

Secondly, siblings are a good match to be a living donor because not all donors are a good match for the child and there can be issues with having the organ rejected.⁷ Siblings share a great deal of the same genetic material and having a donation from a

³ R. Grant Steen & Joseph Mirro, Jr., Childhood Cancer 158 (2000); Marie Bakitas Whedon, Bown Marrow Transplantation 110 (1991). Both sources state that identical twins share the same genetic makeup and are the best donors for each other.
⁴ Id.
⁵ As of November 2009 there were a little over 82,800 people on the waiting list to have a kidney transplant. United Network for Organ Sharing, at http://www.unos.org/data (last visited Dec 1, 2009).
⁶ As of November 27, 2009 there were over 1800 children on the waiting list to have at least one transplant. The U.S Department of Health and Human Services, at http://optn.transplant.hrsa.gov/latestData/rptData.asp (last visited Dec. 1, 2009).
sibling might lessen the chances that the organ will be rejected. In addition, a sibling especially a twin is an ideal live donor because another child is often close in size and age which also helps the body accept the organ better. This is true for different types of organs and tissue.

Although it has been established that siblings are the best match to be donors, doctors are faced with a variety of ethical decisions regarding child donors. Even though the first live child donation was done with the consent of the parents, the doctors did not perform any more organ donations from children under the age of thirteen. They decided not to use younger donors in the early transplants because of the concern that they were not able to understand and consent, because children between the ages of seven through eleven are still progressing through the concrete operational stage. This is the stage where they are able to see and understand more than one viewpoint and their egocentric ideas will decrease.

The Issue of Informed Consent

Many doctors and healthcare professionals are concerned with the rights of the minor to consent to organ and tissue donation. Laws concerning minors are not generally regulated federally, instead each state mandates by statute and case law how they deal

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8 Id.
9 Id.
11 Id.
12 Diethelm, supra note 1, at 508-509.
13 Id.
with minors. Because each state has its own autonomy the laws regarding minors and medical treatment including their ability to donate organs vary. Although there are many differences in how each state deals with minors; every state makes a presumption that minors are not treated the same as adults under the law because they do not have enough experience to understand the consequences of their actions.15

Because children are presumptively incompetent their parent or guardian must consent in their place in most states unless they are considered independent, either because they have become parents themselves, married, or they have served in the armed forces.16 In addition, there is an exception for the mature minor. The mature minor is someone that is close to the age of majority and the court believes that they can give informed consent, even in medical cases.17 Some states have statues that allow even minors who are not independent to make decisions concerning their health, but none of those states give minors the right to have nontherapeutic medical procedures like tissue or organ donation.18 A nontherapeutic medical procedure is one that has no health benefit to the person receiving the treatment.19 In the case of organ or tissue donation the donor is receiving a nontherapeutic procedure because they will not receive any medical benefit

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16 Judith C. Areen, Cases And Material on Family Law 1030-31 (2d ed. 1985).
18 Nancy Batterman, Under Age: A minor’s Right To Consent To Health Care, 10 Touro L. Rev. 637 (1994).
19 Id.
from the surgery. Unless the minor meets some other statutory exception the parents of the child are required to give informed consent in order for the child to be a donor.\textsuperscript{20} The courts have established that there is a presumption that the right to consent to organ and tissue transplantation lays in the parent of the child not in the child him or herself. In cases where the parent is so concerned with the sick child that their actions put the donor child at risk the state can exercise its parens patriae power.\textsuperscript{21} Many hospitals and doctors believe that there is a conflict when a parent consents to an organ donation between two siblings, because it is hard for the parents to be impartial and make the best decision for the donor child.\textsuperscript{22} When the parents are so concerned about healing their sick child and they disregard the wellbeing of their donor child their consent is not valid.\textsuperscript{23} Hospitals usually ask for advocates for the donor child in cases of donations between two siblings.\textsuperscript{24}

The donor child’s decision to be a donor is sometimes looked at as a factor but it is not given much weight. The courts do not really inquire into what the donor wants because it has been determined that they are not capable of making that decision for themselves because of their status as a minor. While some critics argue that the decision of the donor should be given more weight, this sounds great but can yield dangerous results. Because the child does not have adult reasoning abilities he may make a decision

\textsuperscript{22} Teena-Ann V. Sankoorikal, Using Scientific Advances to Conceive the “Perfect” Donor: The Pandora’s Box of Creating Child Donors for the Purposes of Saving Ailing Family Members, 32 Seton Hall L. Rev. 583, 603.
\textsuperscript{23} Id. at 604.
\textsuperscript{24} Id. at 603-604.
for himself that he could regret later in life. Suppose that a young child decides not to
give life saving bone marrow to a dying sibling because he is holding a grudge, that child
may regret that decision later in life when he is able to fully understand and appreciate
the situation. The decision whether or not to give lifesaving treatment to a sibling is a
decision that the child should be included in making but it should not be their decision
alone as some might suggest.

The Best Interest of the Child

When someone challenges the parent’s ability to give informed consent the courts
often get involved. There are two main views that most state courts seem to take. Some
state courts make decisions on organ donation based on the best interest of the child
standard while others use the doctrine of substituted judgment.25 The courts that use the
best interest of the child standard base the decision to allow living child donors on a case
by case basis. These courts insist that the child can only be a live donor if it is in the best
interest of the child.26 The courts will look at both the benefits and the risk for the donor
child.27 If the courts just looked at the physical benefits of the surgery then courts would
never be able to conclude that it is in the best interest of the child to have an invasive
surgery, because the child receives no physical benefits. Instead the court will consider a

25 Id. at 606.
26 Id at 606.
27 Bryan Shartle, Comments, Proposed Legislation for Safety Regulating the Increasing Number of Living
variety of factors. Most state courts have paid particular attention to the psychological benefits that the donor child may receive from undergoing the surgery.\textsuperscript{28}

Most states courts that use the best interest of the child standard believe that it is in the best interest of a child to have a strong relationship with their sibling and to have their family kept intact.\textsuperscript{29} The family structure is very integral to the development of a healthy child. It is well established that keeping a family intact, in most situations is a good thing. That means that it is good to have the mother, father, and all the siblings in the same household if possible. States that use the best interest of the child standard do not take into consideration the wishes of the child.\textsuperscript{30} The wishes of the child are disregarded because they are not considered competent under the law and their parents are their decision makers, either until they reach the age of majority or they meet some other statutory exception.

If the court concludes that allowing the healthy child to be a donor is in his or her best interest then the court will approve the surgery.\textsuperscript{31} Although there is no uniform federal law that regulates the states treatments of minors all state courts recognize that in making a decision concerning minors, the best interest of the child has to be taken into consideration.

\textsuperscript{28} G. Pennings, R. Schots & I. Liebaers, Opinion, Ethical Considerations on Preimplantation Genetic Diagnosis for HLA Typing to Match a future Child as a Donor of Hematopoietic Stem Cells to a Sibling, 17(3) Human Reproduction, 536 (2002).
\textsuperscript{29} Id. at 536.
\textsuperscript{30} Sankoorikal, supra note 16, at 606.
Some scholars believe that the physical burden created by the surgery is so great that it is normally not in the best interest of the child to be a donor. In addition, scholars who are concerned with protecting children’s personal autonomy believe that the courts incorrectly allows sibling donors based on the best interest of the child standard. Because short of immediate death or serious injury the best interest of the child standard will always yield the result of allowing the child to be a sibling donor. These legal scholars believe that it creates a great hardship for the donor child because the process does not respect their liberty interest to be free from physical invasion.

Opponents of minor sibling donations believe that the long term effects are not given enough weight. They believe that there is a chance that the donor sibling might need the donated tissue or organ for their own use and it will not be available to them later in life because of a decision to donate made by their parents when they were younger and had no say in the matter. It is valid concern to worry about the donor child’s well being, but the opponents of minor donations often swing to one extreme. They seem to be overly concerned with making sure that the donor child does not have decisions concerning their body made for them. This idea is one that is contrary to the status of minors and places too much weight on the donor child’s rights, when it has already been determined by law that the parents are in the best position to exercise a child’s rights on their behalf. In addition the best interest of the child standard seems to be a fair standard because there is no way to compare and measure the value of a child.

33 Id.
34 Id. at 77.
35 Id. at 77.
being able to help keep a sibling alive when there is very little risk to the donor child himself.

Although there are many opponents to the way the courts apply the best interest of the child standard it still is the leading doctrine used to decide whether a sibling should be allowed to be a donor. One noted recent case that applies the best interest of the child standard is In re Sidney Cowan. This case involves two twin girls one of whom was injured in a fire. The twin girls live in a family home with both their parents. In December 2002 Mr. Cowan was lighting the fire place and it exploded injuring Jennifer. She was badly burned over 80% of her body. The doctors calculated a very low chance of survival, but Jennifer’s situation improved over a few weeks. The doctors did the best they could to use Jennifer’s existing unburned skin to cover the burned parts of her body but it was just not enough.

The doctors realized that Jennifer would need more skin. They believed that her twin sister would be the best candidate because they are identical and therefore have the same genetic makeup. Because there was established medical material and case law relevant to this kind of situation, the hospital was aware of the ethical issues of having a sibling donor. The hospital ethical committee interviewed the twin girls and their parents and determined that Sydney should be allowed to donate skin to her sister. The hospital ethics committee based this finding on the fact that it was in the best interest of Sydney to

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36 In re Sidney Cowan, No. 180564 (Probate Court of Jefferson County, Ala. 2003).
37 Id.
38 Id.
39 Id.
donate skin to her sister because it would allow her to continue her close personal relationship with her sister, and psychological examinations by the hospital did not reveal that the donation would cause any damaging emotional effects. The hospital was still cautious to the sensitive nature of sibling organ donation so they required a court order to operate.

The parents petitioned the court for authorization to perform the procedure and a Guardian ad litem was appoint for each of the girls. The court used the same factors as the hospital ethical review committee and granted the parents the right to give informed consent to have Sydney be a donor for her twin sister. The court reasoned that it was in the best interest of both children to have the surgery and as long as the parents of the girls were aware of the physiological and psychological risk and benefits, they were fit to give informed consent for the donation to take place.

Critics of this case might point out that there were other donors who could have donated skin for Jennifer, and that although Sydney was the best match as a donor the harm done to her by placing her in this position both emotionally and physically outweighed the benefits Jennifer gained by having a perfect match. These critics may over look the point that the sisters were close and although the law gives no deference to Sydney’s personal opinion, she wanted to help her sister. Helping those in need is both beneficial to society and a biblical principal. It was stated in the case that Sydney may also suffer emotional damage if she were not allowed to help and her sister suffered a

41 Id.
42 Id.
43 Id.
44 In re Sidney Cowan, No. 180564 (Probate Court of Jefferson County, Ala. 2003).
rejection of the other donor tissue and died. In addition, there was a very low chance of harm coming to Sydney because of the surgery but a great benefit to Jennifer.

**Parental Informed Consent in Case Law**

Sidney Cowan’s case was just one of a handful of cases that has resulted from the growing number of minors who are serving as donors for siblings. Hart v. Brown is an earlier case that also followed the same line of reasoning. In this case the court did not use the best interest of the child standard but its reasoning was very similar. The court ruled that a seven year old girl could be a kidney donor for her twin sister because it was viewed as favorable for the children because it supported the views of community including members of the clergy. The best interest of child standard takes into account the relationships that the siblings share with each other and how the donor’s relationship with other in the family will be affected by the donation. In *Hart* the court looks at these factors as well as going back to the accepted principal that the parents have the right to direct the upbringing of their children and that the parents’ informed consent was enough to allow the transplant to take place.

The court in *Hart* did not want to interfere with the right of the parents to bring up their children. The court looked at the views of the community because as long as the community did not view the transplant as repulsive to public policy the courts did not want to interfere with their decision. In this case, the community agreed with the parents

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45 Id.
46 Id.
48 Id.
50 Hart, 289 A.2d at 391.
and even the clergy believed that this was something that would be in the best interest of the family. The court most likely looked to the community standard because although parents do have the right to direct the upbringing of their child this is not an absolute right that cannot be checked by community to ensure the safety of the child. While some courts grant parents the right to make a child a donor because of their right to direct the upbringing of the child, other courts grant the parents this same right through the doctrine of substituted judgment.

**Substituted Judgment**

Some states like Texas have adopted the doctrine of substituted judgment. This doctrine is often applied not only to minors but also to incompetent adults who have others making decisions on their behalf. The Texas Supreme Court has determined that the doctrine of substituted judgment means that the court will substitute itself as close as possible for the incompetent and make a decision that they believe the incompetent if they were able to make a decision. In the *Little* case the mother of a fourteen year old with Down’s syndrome wanted the girl to donate a kidney to an older brother who was very sick. The brother may have died if he was not given a kidney. Although the court states that it is using the doctrine of substituted judgment, it uses the same factors as the best interest of the child standard. The court in *Little* looked at the relationship between the siblings. The court concluded that the siblings were very close and that the loss of her brother may be more damaging than the actual surgery, in addition the court found that the surgery would likely save the brother. In addition, it reasoned that although the

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51 Little v. Little, 576 S.W.2d 493, 497 (Tex. Civ. App. 1979)
52 Id.
53 Id at 498.
girl is incompetent and therefore unable to give consent, it appears that she gave her consent free from any undue pressure by her family.\textsuperscript{54} After considering these factors the court was able to determine that if the girl could give consent to the surgery she would.\textsuperscript{55}

Critics argue that the doctrine of substituted judgment has no place in juvenile law because this it is hard to say what a child would do if they were older because their belief system and experiences would shape the way that they would feel about different issues.\textsuperscript{56} The critics point out that the child’s views can just be merely guessed at best because the child has always suffered from their condition and their true will cannot be known.\textsuperscript{57} Some would say that this doctrine is best used on incompetents who were once competent.

Although those who do not agree with the doctrine of substituted judgment have some valid points it seems that they overlook that fact that a parent of a child can reasonably expect that the child will share a similar value system as the family. Although it is true that the child could have a completely different set of values when they reach the age of majority, many children still would share the same core value beliefs as their parents. The idea of allowing parents to direct the upbringing of their child assumes that some of the values the parents are placing in their child will remain. It appears that the biggest problem the courts face when dealing with substituted judgment is deciding how far to allow this doctrine to go.

\textsuperscript{54} Id.
\textsuperscript{55} Id.
\textsuperscript{56} Michael T. Morley, Proxy Consent to Organ Donation By Incompetents, 111 Yale L. J. 1215, 1235 (2002).
\textsuperscript{57} Id.
Some courts have decided to limit this doctrine and require either the consent of the incompetent or that the incompetent receive some benefit.\textsuperscript{58} In \textit{In re guardianship of pescinski} the court ruled that the guardian of an incompetent adult could not consent to have the incompetent give a kidney to his sister even though she would likely die without the surgery.\textsuperscript{59} The court found that there was no benefit to the incompetent because he did not even have a close relationship with the sister.\textsuperscript{60} It is likely that the incompetent did not have a strong relationship with his sister because his schizophrenia may have prohibited him from doing so.

It appears that the court in \textit{Pescinski} draws a fine line to limit the power of substituted judgment. This case and cases like it are important because they require that the incompetents including minors gain at least some benefit from being a donor, even if the benefit is purely mental. This prevents the incompetents from being used for spare parts and makes sure that their interests are protected.

\textbf{The Intent of the Different Standards Determining Sibling Organ Donation}

It seems that state courts all over the United States want to protect the rights of children and parents. All the standards look at what is best for the donor child, but they all acknowledge the family unit and the role that the each member of the family plays in the life of the donor child. In addition, all the different standards used seem to realize that it is in the best interest of the child to do what is in the best interest of the family as a whole because the child is a functioning member of the family.

\textsuperscript{58} In re Guardianship of Pescinski, 226 N.W. 2d 180 (Wis. 1975).
\textsuperscript{59} Id at 180.
\textsuperscript{60} Id.
Although sometimes the best interest of the child and the best interest of the family seem in conflict, they are not. Even if donating an organ to a sibling may seem like it may not be good for the donor child, the donor child does receive the benefit of keeping the family together. In addition, it could be bad for a child who could donate tissue or a spare organ to see their sibling die because they were not permitted to help even though there would be very little lasting physical effects to the donor child.

The courts that look to parental informed consent are also concerned with the same matter. These courts believe that the parents of the children are in the best position to make a decision for their child; in addition these courts try to give parents the freedom they need to direct their family in the best manner they see fit. This standard is a good standard because it limits the parents to acts that are accepted by the community. In addition, this standard also does a good job of protecting the interest of the donor child because parents are often the biggest advocates for their own children and most want to keep their entire family intact not just keeping the sick child alive.

Even though some critics believe that the parents are not in the best position to consent to sibling donors, courts have consistently allowed parents to make decisions concerning sibling donors. The critics argue that the parents are so concerned with the sick child that they are willing to sacrifice a well child to get the sick child better. In some cases this may be the situation but there is a very high success rate for sibling donations. In addition, the detriment to the healthy child was usually minimal. Even when the healthy child donated a kidney the child usually recovered.

Jurisdictions that used the substituted judgment standard also looked at some of the same factors as both the best interest of the child standard, and the parental informed
consent doctrine. The courts that used substituted judgment also looked at the relationship and makeup of the family. The courts would look at the relationship the proposed donor had with the child in need as well as if the family was intact and if having the donation would keep the family intact. The court would try to figure out what the child would want to do based on those relationships if they were at the age of majority. This is essentially the same thing as looking at what is in the best interest of the child.

Over all, all of the three different analyses discussed in this paper all are concerned with the well being of the donor child in the family unit. Although they all use slightly different reasoning each of the standards seeks to keep families together by allowing parents to have healthy children donate organs or tissue to help a dying sibling.

**Proposed Changes to the Way Sibling Donors are treated**

It seems that the courts are headed in the right direction in how they deal with sibling organ donation. Parents’ wishes should be given the most weight in these types of situations because the parents are in the best position to decide what to do when it comes to sibling organ donations. In addition to looking at the wishes of the parents, the wishes of the child should also be considered. Although their decision should not be given too much weight, efforts should be made to help the child understand the situation as much as possible. If the child is too young to understand the gravity of the situation then the surgery should only be performed if the sick child has no other donor choices.

Although many of the cases had medical experts testify on the medical necessity of the surgery, it seems that there should be a greater effort to explore all other options before very young children are used as donors. It does not seem fair to have a very
young sibling be a donor because they would be the easiest donor. Although donor siblings are the best donors they should only be used if older donors are not an option.

In addition, it would be good for the parents of the children to have more counseling. Many hospitals have counseling for the donor child and the patient. The parents should have counseling and the family as a whole should also receive counseling in order to bring physical healing to the children and emotional healing to the whole family.

Over all, it appears that the courts are doing a good job of looking out for the best interest of the donor child and ensuring that families are kept intact. The hospitals and doctors have raised an ethical standard that has seemed to protect children while still allowing the parents the right to make major decisions concerning their child. Doctors, parents and both the sick child and the donor child working together to keep the family strong seems to be the best idea for keeping sibling organ donation ethical, and a useful tool for families.