# **The Canadian Council for Donation And Transplantation**

# Faith Perspectives on Organ and Tissue Donation and Transplantation

Report

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#### **Foreword**

The issue of faith is crucial in the effort to increase organ and tissue donation and transplantation in Canada, especially in regards to donation after death. At death's door, people are extra careful not to violate faith dictates. Also, it is the time when the family's clergy are likely to be very involved, and sought after for advice and counsel.

We can put into place all the necessary ingredients for donation and transplantation, but if the religion of the prospective donor, or his or her family, says no to this life-saving endeavour, then the opportunity for donation may be missed. For organ and tissue donation and transplantation to reach optimal levels, religions need to champion this cause, and to encourage it within their congregations. As well, organizations working to promote donation must consider the aspect of faith in personal decisions about the donation of organs and tissues.

With this in mind, CCDT brought together a wide array of religious leaders for a forum on this subject in March 2005. Prior to the forum, religious groups were polled through telephone conversations with appropriate representatives of the respective faiths. Additionally, the literature on this topic was combed for further elucidation of the positions of the religions on organ and tissue donation and transplantation.

The forum brought together an unprecedented array of religions, a gathering which was a first in Canada for this topic. The forum was an opportunity for the faith representatives to learn more about the topic, and to look at the challenges that they face in promoting organ and tissue donation within their faith communities.

The forum was conducted in a spirit of camaraderie and common purpose, and concluded with a virtually unanimous desire to pursue this as a priority. This report conveys the issues discussed, and concludes with recommendations on how to further integrate the clergy into the organ and tissue donation process.

Critical to this most promising beginning were the contributions of Kimberly Young, Beverley Curtis, and Dr. Rosalie Starzomski, Chair, Ethnocultural Steering Committee. They, together with other CCDT staff, put together an experience which was most appreciated by all who attended. Following up on this forum is critical to the ultimate success of all our efforts at CCDT.

Rabbi Reuven Bulka, Lead, Inter-Faith Committee



# **Section 1: Background**

The Canadian Council for Donation and Transplantation (CCDT) was established in 2001 as an advisory body to the Federal, Provincial and Territorial Conference of Deputy Ministers of Health in response to concerns about a persistent and growing gap between the demand for and the supply of organs and tissues for transplantation in Canada. The CCDT supports efforts to coordinate federal, provincial and territorial activities in the development of standards, policies and best practices for organ and tissue donation and transplantation.

The initial focus of the CCDT was creating opportunities for health professionals and other stakeholders to reach agreement on clinical practices. Four meetings were held to examine clinical aspects of organ and tissue donation – neurological determination of death, medical management of organ donors, immunologic risk in transplantation and donation after cardiocirculatory death. For more information about the CCDT and its initiatives, see www.ccdt.ca.

The CCDT recognizes that the decision to donate organs and tissues involves more than medical considerations. Many people make important decisions in consultation with their faith leaders and in reference to their faith's teachings and traditions. This is especially true when families are facing the traumatic experience of a death of a loved one. Donation opportunities are sometimes lost when health professionals do not approach families whose faith they believe does not support donation. In other cases, opportunities are lost when families decline to donate because they are unaware of their faith's position on donation and transplantation. As a consequence, people do not receive much needed transplants and lives are lost.

The CCDT developed a three-point approach to understand the perspectives of faith communities and to develop a collaborative agenda for action. The approach included:

- 1. Searching the literature to gain an understanding of the published work on the positions of faith groups on organ and tissue donation and transplantation;
- 2. Surveying faith leaders in Canada to identify current views and activities of faith groups in relation to donation and transplantation; and
- 3. Hosting a forum of faith group leaders to consult on the best ways to work together to increase awareness about organ and tissue donation and transplantation among people who rely on their faith for guidance.

The results of the first two activities (selected literature review and telephone survey) provided the background research to inform the development of the inter-faith forum.

# **Section 2: Literature Review**

The objective of the literature review was to summarize the viewpoints of the major faith groups in Canada towards organ donation and transplantation. The literature review included a review of published viewpoints towards brain death, death, and treatment of the deceased by faith groups.

The objective was met through a 4-step process:

#### Developing specific search questions and key words to guide the review, including:

- What are the major religions in Canada?
- Do the major religions recognize brain death?
- How do the major religions treat the process of dying and the deceased?
- Do the major religions accept and support organ donation?

Concepts used in the search included key words and subject headings such as: religions (e.g., religious belief, Judaism, Islam, Christianity), death (e.g., brain death, attitude to death, cadaver) and transplantation/donation concepts (e.g., transplant donor, heart donation, organ transplantation, tissue transplantation).

# 2. Determining the parameters of the literature search.

The search was done in US National Institutes of Health PubMed database, Cumulative Index to Nursing and Allied Health Literature (CINAHL) database, American Theological Library Association (ATLA) and the Internet using Google.

The dates searched were from 1966 to current 2004 for PubMed, 1982 to current 2004 for CINAHL and 1949 to current 2004 for ATLA. Most of the references for the search are therefore from 1990-2004.

#### 3. Conducting the search.

A systematic search was undertaken, searching the following databases:

- PubMed, which yielded 203 articles;
- CINAHL, which yielded 16 articles (9 were duplicates of the PubMed search); and
- ATLA, which yielded 18 articles.

# 4. Reviewing articles for relevance to the search parameters and questions.

The retrieved articles were screened according to the following criteria:

- Date published: articles published after 1985 were reviewed;
- Quality: an article was considered to be of higher quality if it contained a greater number of references and if it were a research study; and
- Relevancy to the search questions: an article had to address at least one of the following to be included:
  - At least one of the aspects identified in the search questions;
  - A faith group's beliefs related to organ donation and/or transplantation; or
  - A faith group's beliefs related to the process of dying, death or burial.

<sup>&</sup>lt;sup>i.</sup> Brain death is the common lay term for the neurological determination of death.

## 2.1 Summary of Findings

Views of the major faith groups that were found in the literature could be described as:

Support: faith groups that have actively spoken out on organ and tissue donation and transplantation in a positive manner and encourage their followers to become organ donors.

Accept: faith groups that accept the idea of donation and transplantation, but do not publicly advise their followers to take a specific course of action.

Neutral: faith groups whose teachings or philosophies do not oppose donation and transplantation; however, they do not openly support it either.

Against: faith groups that either speak publicly against organ and tissue donation or have teachings and philosophies firmly against organ and tissue donation.

The search found that there is no major faith group that is against organ and tissue donation and transplantation.<sup>1</sup> Most faith groups accept organ and tissue donation. The search identified that the premise behind most faith groups is to do good. Some faith leaders emphasize that this can be accomplished, in part, by donating organs or tissue after death. Some groups express neutral views about donation, leaving the decision to the individual.

All faith groups require respectful treatment of the process of dying and the deceased person, and if respectful processes are followed, donation is acceptable to most faith groups. The majority of faith groups indicated that they do not support compensation or coercion for donation and believe in fair and equitable allocation of organs and tissues for transplantation.<sup>1</sup>

The following section describes the findings of the literature search for Buddhism, Christianity, Hinduism, Islam, Judaism, Shintoism and Sikhism. The numbers appearing above and in the next section refer to the references in which the statement was found. The numbers correspond to the references in Appendix 1.

#### **Buddhism**

Buddhists agree that the dead should be treated with love and respect. <sup>5</sup> Buddhists believe that organ and tissue donation is a matter of individual conscience and there is no written, official position on organ and tissue donation. <sup>10</sup> Buddhists place high value on acts of compassion. Those who support organ donation claim that it:

- 1) is a compassionate, kind and generous gesture;
- 2) de-emphasizes the importance of the body;
- 3) does not interfere with the re-birth of the body (only the soul is re-born), and
- 4) that it accumulates good karma.<sup>1,11</sup>

Those who are not in favour of organ donation state that Buddhism opposes any attachment to life or a disruption of the dying process, with which they perceive that organ transplantation interferes. One scholar states that Buddhism supports organ donation, but not transplantation.

#### **Christianity**

Christians believe in the sanctity and value of a human life and respecting the deceased.<sup>1</sup> The majority of denominations support organ and tissue donation and transplantation, calling it a demonstration of Christian love.<sup>9</sup> There are no objections to brain death as defining death and almost all denominations uniformly favour neurological definition of death. The Christian faith believes in bodily resurrections and its teachings state that, since the resurrection occurs with a new and perfect body, removing organs for transplant does not impede resurrection.<sup>1</sup>

In his Encyclical letter Evangelium Vitae, Pope John Paul II suggested that one way of nurturing a genuine culture of life "is the donation of organs, performed in an ethically acceptable manner, with the view to offering a chance of health and even of life itself to the sick who sometimes have no other hope." (No. 86) The Pope mentions that, as with all issues related to life, ethical considerations must be taken into account.<sup>1</sup>

#### **Mormon Faith**

The Church of Jesus Christ of Latter-day Saints believes that the decision to donate is an individual one made in conjunction with family, medical personnel, and prayer. They do not oppose donation.<sup>ii</sup>

#### Hinduism

Hindus are particular about who touches the deceased and believe in cremation to return the body to the earth. Organ transplantation is accepted and is regarded as virtuous behaviour. According to the Hindu Temple Society of North America, Hindus are not prohibited by religious law from donating their organs. This act is an individual's decision.

H. L. Trivedi, in Transplantation Proceedings, stated that, "Hindu mythology has stories in which the parts of the human body are used for the benefit of other humans and society. There is nothing in the Hindu religion indicating that parts of humans, dead or alive, cannot be used to alleviate the suffering of other humans." The basic tenet of Hinduism is to help those who are suffering. Hinduism traditionally associates death with respiratory failure but there is no formal resistance to a neurological determination of death.

#### **Islam**

The tenets of Islam prescribe that the body is sacred and belongs to God.<sup>6</sup> People who follow Islamic traditions believe that it is their duty to aid others and that all possible legal means should be taken to save a life.<sup>7</sup> The majority of Islamic experts favour organ donation and transplantation and reconcile the principles of saving a life against respecting the cadaver.<sup>8</sup> There are guidelines for donation which state that donation can only occur if:

- 1) no other treatment is available;
- the transplant has a good chance of success;
- voluntary consent is obtained from the donor or from the next of kin; and
- 4) death has been accurately pronounced.<sup>1</sup>

The majority of Islamic scholars recognize brain death. Although there are views against organ donation and transplantation in Islam, a prominent Muslim physician-medical ethicist states that "necessities overrule prohibitions". In other words, since organ and tissue donation can either save or enhance a person's life, the act of donation is more necessary than observing the prohibitions.

ii. Found on the World Wide Web at http://www.donor-awareness.org/info.religious.html on June 14, 2005.

#### **Judaism**

All four branches of Judaism (Orthodox, Conservative, Reform and Reconstructionist) support and encourage donation. The highest value in Judaism is to emulate God through acts of love, compassion and concern. Jewish law considers organ donation and transplantation as one of these acts.<sup>4</sup> Many Rabbis support organ donation through the tenet that to save one life is to save the whole world. Pikuach nefesh, the saving of human life, is the overriding value which permits donation. According to Orthodox Rabbi Moses Tendler, Chairman of the Biology Department of Yeshiva University in New York City and Chairman of the Bioethics Commission of the Rabbinical Council of America, "If one is in the position to donate an organ to save another's life, it's obligatory to do so, even if the donor never knows who the beneficiary will be. The basic principle of Jewish ethics - 'the infinite worth of the human being' - also includes donation of corneas, since eyesight restoration is considered a life-saving operation."iii

There is a mandatory obligation to use all means to save or prolong the life of another person. The majority accept the diagnosis of death based on both neurological and cardiopulmonary criteria.<sup>2</sup> There is some disagreement within Judaism with some Rabbis only accepting the cardiopulmonary criteria as means of diagnosing death;<sup>1</sup> however the Israeli Chief Rabbinate endorses neurological determination of death as reliable.

According to Jewish law, transplantation is allowed if the act of transplantation does not hasten death, is performed with respect for the deceased and that body parts that are not used for transplantation are buried with the deceased.<sup>5</sup>

#### **Shintoism**

Shintoism believes that the body is polluted after death, and that someone is not fully dead for 49 days. Although there is little literature on this faith's position on organ donation, some writings suggest that Shinto followers doubt that procuring organs is a polite way to show respect for one's ancestors.¹ Procurement is also viewed as injuring the dead body and to Shinto followers, this is a serious crime.<sup>5,12</sup> It has been documented that even if a deceased person consents to organ donation, the family may override the decision to donate to avoid injuring the dead body and the fear of making the dead person's soul more miserable.<sup>12</sup>

#### **Sikhism**

There is little literature discussing the Sikh view towards organ donation and transplantation. It has been reported that Sikhs accept organ transplants.<sup>1,13</sup> Sikh philosophy and teachings place great emphasis on the importance of giving and putting others before oneself. It also stresses the importance of performing noble deeds, and there are many examples of selfless giving and sacrifice in Sikh teachings by the ten Gurus and other Sikhs. Sikhs believe life after death is a continuous cycle of rebirth but the physical body is not needed in this cycle – a person's soul is their real essence.

iii. Found at http://www.organtransplants.org/understanding/religion/ on February 20, 2005.



Major faith groups in Canada were identified on the basis of Statistics Canada's 2001 census information. Individual provinces were grouped into five geographical regions: Atlantic, Ontario, Quebec, the Prairies and British Columbia. The Atlantic region included New Brunswick, Newfoundland, Nova Scotia and Prince Edward Island. The Prairie region included Alberta, Manitoba and Saskatchewan. The 2001 Census 'Top 10 religious denominations' for each geographical region was used to determine the faith groups with largest numbers of persons.

Major religious denominations, Canada, 1991 and 2001<sup>1</sup>

2001		1991		0/ 0/ 0/ 0/ 0/ 0/ 0/ 0/ 0/ 0/ 0/ 0/ 0/ 0	
Number	%	Number	%	% change 1991-2001	
12,793,125	43.2	12,203,625	45.2	4.8	
8,654,845	29.2	9,427,675	34.9	-8.2	
479,620	1.6	387,395	1.4	23.8	
780,450	2.6	353,040	1.3	121.1	
579,640	2.0	253,265	0.9	128.9	
329,995	1.1	318,185	1.2	3.7	
300,345	1.0	163,415	0.6	83.8	
297,200	1.0	157,015	0.6	89.3	
278,415	0.9	147,440	0.5	88.8	
4,796,325	16.2	3,333,245	12.3	43.9	
	Number 12,793,125 8,654,845 479,620 780,450 579,640 329,995 300,345 297,200 278,415 4,796,325	Number % 12,793,125 43.2 8,654,845 29.2 479,620 1.6 780,450 2.6 579,640 2.0 329,995 1.1 300,345 1.0 297,200 1.0 278,415 0.9 4,796,325 16.2	Number         %         Number           12,793,125         43.2         12,203,625           8,654,845         29.2         9,427,675           479,620         1.6         387,395           780,450         2.6         353,040           579,640         2.0         253,265           329,995         1.1         318,185           300,345         1.0         163,415           297,200         1.0         157,015           278,415         0.9         147,440           4,796,325         16.2         3,333,245	Number         %         Number         %           12,793,125         43.2         12,203,625         45.2           8,654,845         29.2         9,427,675         34.9           479,620         1.6         387,395         1.4           780,450         2.6         353,040         1.3           579,640         2.0         253,265         0.9           329,995         1.1         318,185         1.2           300,345         1.0         163,415         0.6           297,200         1.0         157,015         0.6           278,415         0.9         147,440         0.5	

<sup>1.</sup> For comparability purposes, 1991 data are presented according to 2001 boundaries.

The faith groups are listed in descending order of frequency for each region.

**Atlantic:** Roman Catholic, United Church, Anglican, Baptist, Pentecostal, Salvation Army, Presbyterian, Lutheran, Jehovah Witness.

**British Columbia:** Roman Catholic, United Church, Anglican, Islam, Sikhism, Baptist, Lutheran, Buddhist.

**Ontario:** Roman Catholic, United, Anglican, Judaism, Islam, Baptist, Presbyterian, Hinduism.

**Prairies**: United Church, Roman Catholic, Anglican, Lutheran, Baptist, Church of Jesus Christ of Latter Day Saints (Mormon), Islam, Ukrainian Catholic.

**Quebec:** Roman Catholic, Islam, Judaism, Anglican, United Church, Greek Orthodox, Buddhism.

Based on the above information, the following seventeen (17) faith groups were contacted for a telephone interview: Anglican, Baptist, Buddhist, Church of Jesus Christ of Latter Day Saints (Mormon), Greek Orthodox, Hinduism, Jehovah's Witnesses, Judaism, Islam, Lutheran, Pentecostal, Presbyterian, Roman Catholic, Salvation Army, Sikhism, Ukrainian Catholic, and United Church.

Organizations affiliated with each faith group were identified based on information from the Department of National Defense "Religions in Canada" website (http://www.forces.gc.ca/hr/religions). Telephone contact to faith group leaders within these organizations was the first step in identifying people to be interviewed. Faith group leaders either agreed to participate in the interview or referred the interviewer to other contacts.

<sup>2.</sup> Includes persons who report "Christian", as well as those who report "Apostolic", "Born-again Christian" and "Evangelical".

 $<sup>1 \</sup>quad Found \ at \ http://www12.statcan.ca/english/census01/Products/Analytic/companion/rel/canada.cfm \ March \ 20, \ 2005.$ 

## 3.1 Summary of Findings

All of the faith groups referred to their belief in performing good acts for others in need. It is in keeping with this general theme that organ and tissue donation was viewed as fitting in the framework of good deeds. Based on fourteen (14) responses, six (6) faith groups have official positions on organ and tissue donation and transplantation, five (5) support organ and tissue donation and transplantation.

The faith groups with an official position include Islam and the Christian denominations of Presbyterian, Roman Catholic, Ukrainian Catholic and United Church. The Roman Catholic Church statement indicates that the Church has "strong support for organ and tissue donation and will encourage them [members] to consider this option as a profound act of charity..." The Ukrainian Catholic Church has adopted the position of the Roman Catholic Church. Official positions of the Catholic and United Churches include both "organ and tissue donation" in their statements. The Presbyterian statement only refers to organ donation. The Islamic faith supports donation of internal vital organs and considers the will of the dying individual as crucial. The Church of Jesus Christ of Latter Day Saints has an official position in which the decision to donate is to be made by the individual after receiving medical counsel and confirmation through prayer. All decisions are respected.

Eight (8) faith groups did not have an official position; however, they expressed positive responses to organ and tissue donation and transplantation during the interview. These included the Christian denominations of Anglican, Baptist, Lutheran, Pentecostal, Salvation Army and the faith systems of Buddhism, Hinduism, Judaism and Sikhism. In some cases, support was implied by published writings. For example, the Anglican Church Journal stated: "...seven Anglican bishops of the ecclesiastical province of

Ontario have unanimously endorsed a statement by the Roman Catholic Bishops of Ontario supporting organ donation." Respondents for the Buddhist and Hindu faiths referred to scripture, which supported the concept of organ donation. In the Hindu faith, The Manusmruty states "of all the things that it is possible to donate, to donate your own body is infinitely more worthwhile." The United Synagogue of Conservative Judaism has adopted a resolution encouraging all Jews to become enrolled as organ and tissue donors. The resolution further urges that potential donors sign and carry cards or drivers' licenses attesting to their commitment of such organs and tissues upon their death to those in need. For Jews, organ donation is a duty, not a choice. Other branches likewise encourage organ donation.

While many faith groups were supportive of organ donation, some stressed the importance of allowing individuals to make their decision without pressure; organ donation should not be commanded and there should be no disciplinary action or imposition of bad feelings if one should choose not to donate.

Though the World Sikh Organization's response to organ and tissue donation and transplantation was positive, there is sensitivity to language used. They noted the need to use correct language and not apply Christian interpretations to Sikhism since some terms (e.g., rituals) are viewed negatively. In this case, the term "traditions" is preferred. With this faith group, there is a need to build trust and respect for their traditions. In particular, the five Sikh kakars must be respected in procedures related to donation and transplantation, and procedures must be carried out with minimum disruption to these. For example, the Sikh Code of Conduct prohibits the removal of hair, which has implications for carrying out surgical procedures.

#### 3.2 Interest in Involvement in Donation Awareness Activities

Some groups indicated that they participate in blood donation drives or sign organ donation cards, but no ongoing, organized donation-supportive activities were reported by any of the faith groups. Activities may occur within local congregations, driven by issues within a particular congregation. For example, in Spring 2005, churches in Saskatoon held a "Share Fest", which is a city-wide effort to mobilize the city to "do good things" such as signing organ donor cards, blood donor drives, and other good work.

The Church of Jesus Christ of Latter Day Saints did not see participation in donationpromotion activities as consistent with their official position; that is, this matter should be left to individual decision and should not be promoted by the Church. Respondents for the Pentecostal and Salvation Army were also sensitive to wording about "promoting" organ donation and, although they indicated an interest in involvement, they would not be interested in actively "promoting" organ donation.

Many faith groups indicated an interest in being involved in discussion at a national level. Affirmative responses were received from the following groups: Baptist, Buddhist, Hindu, Islam, Judaic, Pentecostal, Salvation Army, Sikh, and United Church.

Faith group leaders suggested the following possible activities for involvement:

- Faith groups with national coordinating bodies could distribute information; (e.g., articles in newsletters). The following faith groups have national coordinating bodies: Anglican, Baptist, Lutheran, Pentecostal, Salvation Army, United Church and Catholic Church.
- Religious leaders at the community level need to be supported (e.g., provide prepared materials for them to distribute to members).
- National coordinating bodies are not present for Hinduism, Sikhism, Islam, Judaism and Buddhism. Community-based activities will be more appropriate.
- Within evangelical churches, there is a "community impact movement" (i.e. doing "good things in the community"). Organ donation activities could fit with this framework.
- Sharing stories regarding organ/tissue donation and transplantation activities that faith groups have organized (e.g., Share Fest).
- Discussion of issues surrounding approach for donation/consent and educating those who
  approach for donation about faith groups' traditions. There is interest in discussing ethics
  surrounding consent for oneself and providing consent on behalf of someone else.
- Discussion of issues surrounding tissue donation, since this concept is "newer" and there are some "grey" areas such as "whether or not tissue is being sold economic incentives".
- Consultation with faith groups which is not be authoritative.

The results of the literature search and the telephone survey of faith leaders supported the concept of an inter-faith forum of leaders to discuss organ and tissue donation and transplantation, and to determine if there is an interest in nationally coordinated activities.

# **Section 4: Inter-Faith Forum**

In March 2005, the CCDT hosted a meeting of 39 guests, representing the major faith traditions in Canada, the First Nations perspectives, and the organ procurement agencies. A list of names and affiliations of participants can be found in Appendix 3.

The purpose of the gathering was to exchange perspectives and identify challenges and opportunities for enhancing organ donation and transplantation. The forum provided an opportunity for people from the health care community (organ procurement agencies) to dialogue with people from the faith communities, in an effort to understand the faith issues that are inherent in organ and tissue donation and transplantation. It was anticipated that the forum would lead to local partnerships based on relationships begun at the meeting.

Participants discussed four challenge questions:

- 1. What are the resources that you need to meet the challenges you face in addressing the topic of organ and tissue donation and transplantation in keeping with your faith's position or your traditional way of life?
- 2. If you had the resources you needed, what would be the first three things you would do to address the issue of organ and tissue donation and transplantation with your faith group membership or with members of your community?
- 3. What partnerships do you think are essential to achieving the goal of increased donations in keeping with faith traditions?
- 4. What are the challenges you face in facilitating discussions about organ and tissue donation with your faith group membership or with the members of your community?

## 4.1 Summary of Findings

Participants generally agreed that faith groups could help their members to understand their faith's position on donation. For those groups which have an organized hierarchy, there were suggestions about involving leaders in making statements about their faith's position and communicating that to local congregations. For those groups which do not have organized hierarchies, a local approach would be more appropriate and would likely involve partnerships with the local health authority and hospital pastoral care department. Participants emphasized the importance of personal stories to highlight aspects of donation and to engage people in thinking about the issue. Many people believed that the National Organ and Tissue Donation Awareness Week (NOTDAW) would be a good time to highlight the issue and provide resources locally, if possible. Participants suggested that resource constraints within their faith community prevented groups from developing resources locally.

#### Question 1:

What are the challenges that you face in facilitating discussions about organ and tissue donation with your faith group membership or the members of your community?

Many participants emphasized that the resource constraints many faith groups were experiencing meant local development of resource materials related to donation and transplantation was unlikely.

Challenges are listed in descending order of priority as mentioned by participants:

- Pamphlets and videos in which people shared personal experiences with donation and transplantation and in which the need for transplants was quantified would be most effective.
- Sermon/homily support materials about donation and transplantation would be helpful to those who would be presenting the issue before their members. Several people mentioned that resources available for download from a website would also be useful as would participation periodically at a national meeting.
- National awareness initiative could assist in educating the public, clergy and health professionals. It was mentioned that an awareness initiative could emphasize our response to relieving human suffering as part of donation awareness.
- There is some mistrust of doctors, hospitals and the health care system.
- Prevention of the conditions which result in the need for donation and transplantation. Preventable illnesses which result in the need for transplantation ought to be addressed sufficiently.

- Challenge in hospitals is that many people are not connected to a faith system and in these situations pastoral care workers are involved. Pastoral care workers should be included in inter-faith initiatives.
- Difficulty that some members of the public have in discussing matters related to death.
- Lack of training of physicians in sensitivity to faiths and cultures.
- Many faiths and First Nations' spiritual traditions are not centralized and therefore ways of sharing information are not top down but come from within communities. Autonomy of local churches means sharing information is resource intensive.

#### Question 2:

What are the resources that you need to meet the challenges you face in addressing the topic of organ and tissue donation and transplantation in keeping with your faith's position or your traditional way of life?

Resource suggestions are listed in descending order of priority as mentioned by participants:

- Information could be distributed through pamphlets and/or video/CD and/or PowerPoint presentations to churches and funeral homes. An information package could be distributed to churches and other faith gatherings quarterly.
- Participants thought that this information should include personal stories/experiences with donation and transplantation as well as presenting the perspectives of different faith groups.
- A national group should collect personal stories from a variety of faith groups. Entertainment celebrities could be useful to attract attention.

- Written materials from each faith's perspective should be made available to assist in writing sermons or messages. Material should include quotes from faith group authority if there is one.
- Faith leaders should speak out together to illustrate shared and common interest in this subject.
- Health professionals need to be better educated about faith perspectives on health care (e.g., the person is more than a body – spiritual aspects of health and illness).
- Community faith leaders should become involved with local hospitals to gain an understanding of donation first hand.

#### **Question 3:**

If you had the resources you needed, what would be the first three things you would do to address organ and tissue donation and transplantation with your faith group or members of your community?

Resource suggestions are listed in descending order of priority as mentioned by participants:

- Educate people, have knowledgeable people go to where the people gather; for example for First Nations people, Pow Wows and Treaty Days would be a good place to educate.
- Have faith leaders write a letter to their local groups supporting organ donation during organ donation awareness week.
   Need to get this topic on the agenda of faith system hierarchies or local boards or Councils.
- Notion of local champion is important.
   Make copies of donor and recipients' experiences available to congregations.

#### Question 4:

What partnerships do you think are essential to achieving the goal of increased donations in keeping with faith traditions?

Suggestions for partnerships are listed in descending order of priority as mentioned by participants:

- Partnerships locally between faith groups, pastoral care and health care professionals.
   Connect health care providers with interfaith committees locally to get the issue on their agenda for action.
- Partnerships between health regions and local faith groups to encourage speakers to present to faith gatherings.
- Partnerships between faith groups and local organ procurement agency (where they exist).
- Develop a Canadian version of COPE (Chaplains for Organ Procurement Education).
- Develop a donor club or coalition of donor families to make the issue more personal.
- Canadian Council of churches could be a contact for Christian denominations.
- For Christian denominations, work with Bible Colleges.
- Canadian Parish Nursing Association.
- Mothers Against Drunk Driving.



The Inter-Faith Forum participants made the following recommendations:

- The CCDT to convene a Faith Advisory Committee to meet to address issues related to faith and donation and transplantation. One of the purposes of this committee would be to develop a coordinated action plan for NOTDAW, among other initiatives to be developed. This committee would contain representatives from the major faith groups.
- 2. The CCDT to develop or acquire printed resources (e.g., UK Transplant or American Donate Life) adapted to the Canadian context and for distribution to faith leaders at the community level.
- The CCDT and provincial organ procurement agencies to explore opportunities to partner with national organizations, such as the Canadian Council of Churches, the Canadian Council of Imams and the World Sikh Council, to promote awareness of organ and tissue donation and transplantation.
- 4. The CCDT to ensure that the information gathered at the Inter-Faith Forum is linked with the CCDT Public Awareness and Social Marketing initiative to collaboratively address issues wherever possible.
- 5. The CCDT to convene a meeting of Canadian hospital chaplains, based on the COPE model, to integrate chaplains into the organ and tissue donation processes in hospitals.

## **Conclusion**

Some people are not sure if their faith would support them in their decision to donate their organs or tissue after death. This uncertainty can result in lost donation opportunities and ultimately in lost lives. We have learned that all major faith systems in Canada support donation and would welcome help in preparing resources and developing partnerships that would assist them in supporting their members to consider donation, and to talk to their family about their decision.

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# Appendix B: Telephone Survey Guiding Interview Questions

#### **Section A: Official Faith Perspective**

- 1. Does your religion/faith have an official perspective on *organ* donation and transplantation? If yes, please describe.
  - a) Describe an example of how your religious perspective would be communicated in a situation when organ donation is being considered for deceased donation.
- 2. Does your religion/faith view differ for deceased vs. living organ donation? If yes, please describe.
- 3. Does your religion/faith view for living organ donation differ for regenerative (i.e., liver) vs. non-regenerative organs (kidney)? If yes, please describe.
- 4. Does your religion/faith have an official position on *tissue* donation and transplantation (e.g., bone, skin, bone marrow)? If yes, please describe.
  - a) Does your religion/faith view differ for deceased vs. living *tissue* donation? If yes, please describe.
- 5. Do religious leaders in your faith discuss *organ and tissue* donation openly with the congregation (e.g., sermon) or are members left to consider the topic individually?
- 6. Are there any written document(s) that would help us to understand your faith's perspective?

#### **Section B: Members' Opinion of Organ Donation**

- 7. What is your perception of the opinion of the members of your faith tradition regarding the following:
  - a) Deceased organ donation and transplantation?
  - b) Living *organ* donation and transplantation (i.e., non-regenerative and regenerative organs)?
  - c) Deceased tissue donation and transplantation (e.g., bone, skin, bone marrow)?
  - d) Living tissue donation and transplantation?
- 8. Do you perceive that member opinions on *organ and tissue* donation and transplantation differ from the traditional/official faith's view? If yes, what factors contribute to this disparity?

#### **Section C: Other Issues**

- 9. Are there rituals, specific to your faith tradition, surrounding death and the handling of a deceased person's body that might negatively affect people's willingness to donate? If yes, please describe.
- 10. Are there any ceremonies, rituals or other activities specific to your faith tradition that may facilitate a family's decision to donate? If yes, please describe.
- 11. Are there any obstacles to overcome in facilitating donation? If yes, please describe.

#### **Section D: Involvement in Organ Donation Activities**

- 12. Does your religious/faith group have any organized activities regarding organ and tissue donation/transplantation? If yes, please describe.
- 13. Would your religious/faith group be interested in becoming more proactive in addressing organ and tissue donation/transplantation?
- 14. Would your religious/faith group be interested in becoming involved nationally with other faith tradition leaders in discussing the issue and considering strategies to become more actively involved in promoting organ and tissue donation/transplantation?
- 15. Does your religious/faith group participate in National Organ Donation Awareness Week? If no, would you be interested in getting involved during that week to promote donation?
- 16. Is there anyone else with whom we should speak?
- 17. Are there written materials related to this topic that we should consult?

# **Appendix C: Inter-Faith Forum Participant List**

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Program

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Bishop of Rimouski Rimouski, Quebec

Ms. Tracy Brand

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Reverend Grant Ikuta

Toronto Buddhist Church

Toronto, Ontario

Reverend Dr. Dale Johnston

President, Canadian Association for Pastoral

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Mr. Sushil Kalia

Past President, Hindu Society of Alberta

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Associate Professor at UVIC and a Clinical Ethicist for the Vancouver Coastal Health Authority

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