

# **Increasing Awareness of Donation and Understanding the Reasons People Don't Register in Areas of Lower Donor Designation**

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## **EXECUTIVE SUMMARY**

Donor Alliance is the federally-designated, non-profit organ procurement organization serving Colorado and most of Wyoming. There are 58 organ procurement organizations in the United States that are responsible for two main functions within their designated service areas: increasing the number of registered donors and coordinating the donation process when actual donors become available.

In 2011 and 2012 Donor Alliance commissioned a large-scale research project and community outreach campaign to study the public's perception of organ, eye and tissue donation in areas of lower percentages of registered donors. The initiative aimed to increase knowledge and overall awareness about reasons people don't register to be organ, eye and tissue donors in the state. The campaign specifically targeted populations from three Colorado regions with lower rates of donor registration, and surveyed residents in these areas before and after the educational campaign.

As a result of the campaign and research, Donor Alliance concluded that targeted education and awareness-building activities leads to an increased registration of organ, eye and tissue donors in areas of lower donor designation, but education must be an ongoing effort. Also, many people in these geographic areas continue to believe myths surrounding organ, eye and tissue donation. These myths are resulting in an unwillingness of residents to register as donors. For this reason, it is important for organ procurement organizations and likeminded businesses to continue to educate on the truths of donation to encourage lower performing communities not to let myths stand in the way of saving lives.

## THE SURVEY AND COMMUNITY CAMPAIGN

Donor Alliance set out to examine the public's perception of organ, eye and tissue donation in areas of lower donor designation rates in Colorado and increase knowledge and overall awareness about reasons people don't register to be donors in the state. (Designation rate refers to the rate at which individuals join the state donor registry as a percentage of licensed drivers and ID card holders.)

Donor Alliance's service states, Colorado and Wyoming, consistently rank among the top states for donor designation.<sup>1</sup> The measure of donor designation is generally accepted as the most accurate way to rank a state's success at driving donor registrations and assessing a state's residents' overall willingness to donate. Despite Donor Alliance's high rates of donor designation in Colorado and Wyoming, the organization continually pushes for more registrants in order to maximize the future potential for transplants and ultimately help the people who remain on the waiting list for lifesaving transplants.

Donor Alliance executed a two-part, independently conducted survey in 2011 and 2012 in three regions with lower rates of organ and tissue donor registration.

These regions were defined by clusters of ZIP codes including Aurora (80010, 80011, and 80239), Denver (80216 and 80219) and Pueblo (81001, 81003, and 81004). The surveys questioned residents about their status as registered donors, reasons for not registering, whether or not they had discussed the topic with their families, beliefs about donation, their interest in receiving more information about donation and from which sources they would feel most comfortable receiving additional information regarding the donation process. The surveys also questioned residents about their belief in myths surrounding donation, which were identified in previously conducted research as key reasons why residents chose not to donate.<sup>2</sup>

In between the two surveys Donor Alliance executed a four-month long, multi-layered marketing and PR campaign in the targeted ZIP Codes, which included reaching out to residents with radio, television, public transportation, door hanger and movie theater advertising, educational outreach in churches and schools, editorials in community newspapers and more.

Following the outreach campaign, the second survey was issued to measure change in public perception, sentiments and knowledge. The response level was sufficient to achieve a maximum margin of sampling error of  $\pm 11$  percent at the 95 percent confidence level.



**Did you know?**  
**400 lives are saved on average each year thanks to organ donors from Colorado**

ALL MAJOR RELIGIONS in the United States support organ, eye and tissue donation and see it as the final act of love and generosity.

THE FIRST PRIORITY of any medical professional is to save lives when sick or injured people come to the hospital. Organ and tissue donation does not become an option until death has been declared.

THERE IS NO COST to the donor or their family for organ, eye or tissue donation.

ONE DONOR CAN SAVE up to 8 lives through organ donation and heal more than 100 lives through tissue donation.

APPROXIMATELY 2,000 PEOPLE living in Colorado are waiting for lifesaving organ transplants.

**Register to be an organ, eye and tissue donor**

Get a  on your driver's license or visit [DonateLifeColorado.org](http://DonateLifeColorado.org)



**Anyone can sign up to be an organ, eye and tissue donor.**

"I have diabetes. I didn't realize I could still donate."

**DONATE LIFE Colorado**

Get a  on your license or [DonateLifeColorado.org](http://DonateLifeColorado.org)

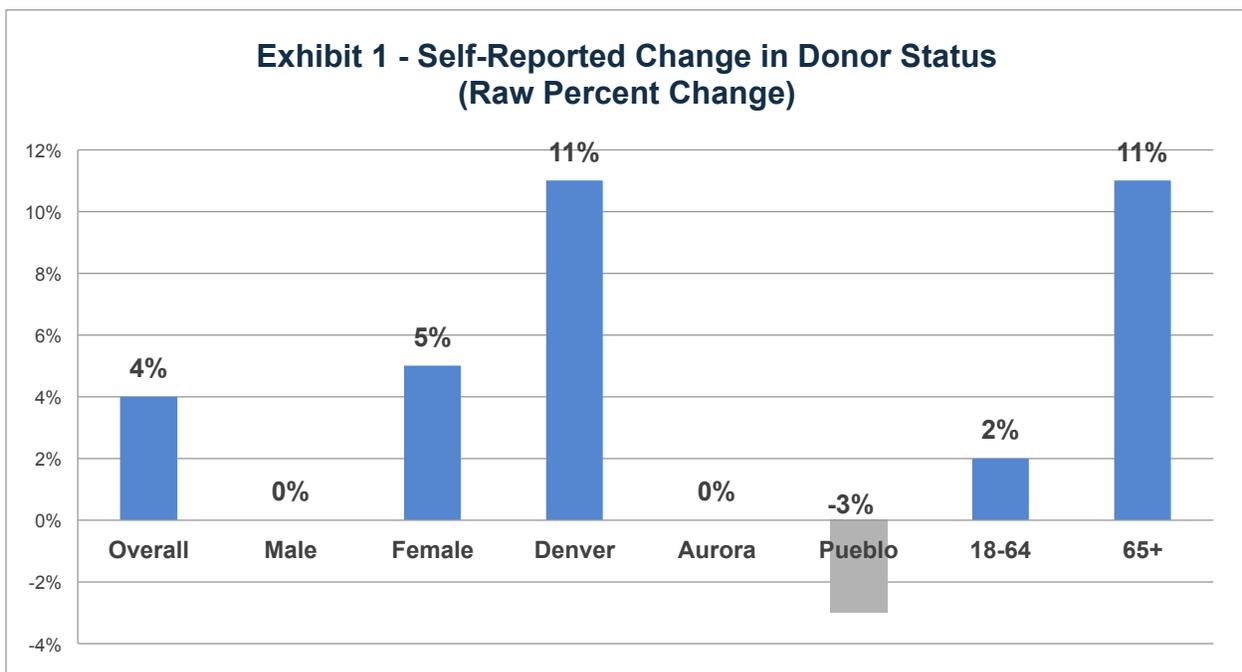
## RESULTS

Surveys pre- and post-community outreach campaign showed key changes in responses from residents.

### Donor registration can increase when targeted outreach occurs

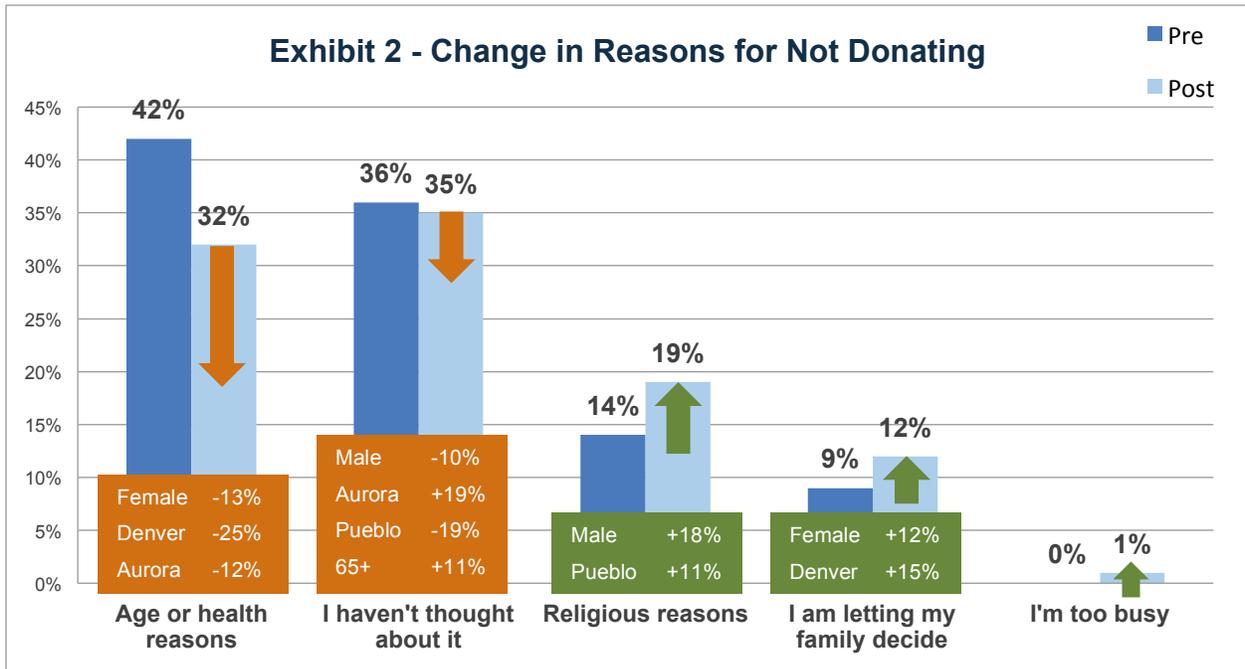
Respondents were asked on pre and post surveys if they had expressed their desire to be an organ and tissue donor. Changes between pre and post survey responses are shown in Exhibit 1 below. Overall, there was a 4% increase in respondents stating they were organ and tissue donors between pre and post survey waves.

Notably, in Denver ZIP codes and among residents 65 or older there was an 11 percent increase. Aurora was unchanged and Pueblo saw a decrease of 3 percent in people registered.



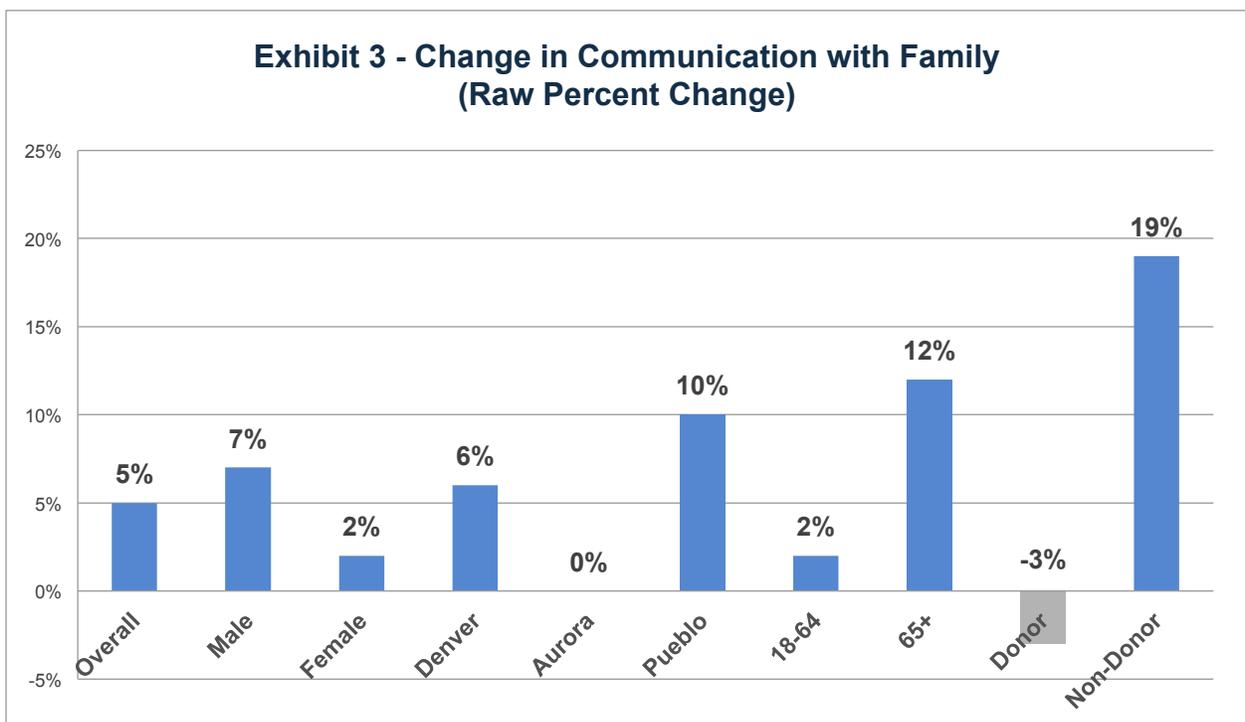
### Many believe health/age precludes them from donating; perception can be changed when addressed directly

Prior to the community campaign, age and health were the primary reasons cited for choosing not to be a donor (42 percent), followed closely by respondents stating they hadn't considered the topic (36 percent). In the post survey respondents citing age and health reasons dropped (32 percent) and respondents claiming not to have thought about becoming donors dropped as well, but became the most cited reason, (35 percent). More details in Exhibit 2.



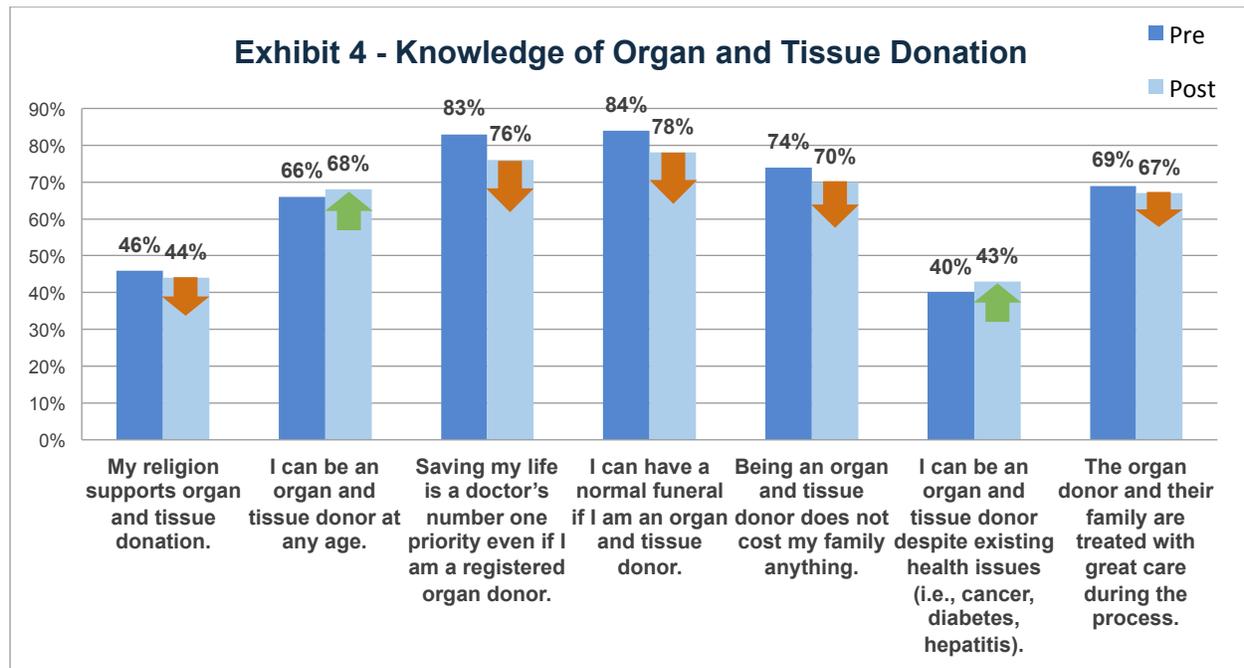
## Awareness-building activities drive residents to think about donation and discuss with their families

Overall, 5 percent more residents shared their donation wishes with their families after the campaign. There was particular growth in this category amongst several demographics: 65 and older (12 percent) and non-donors (19 percent). Further detail in Exhibit 3.

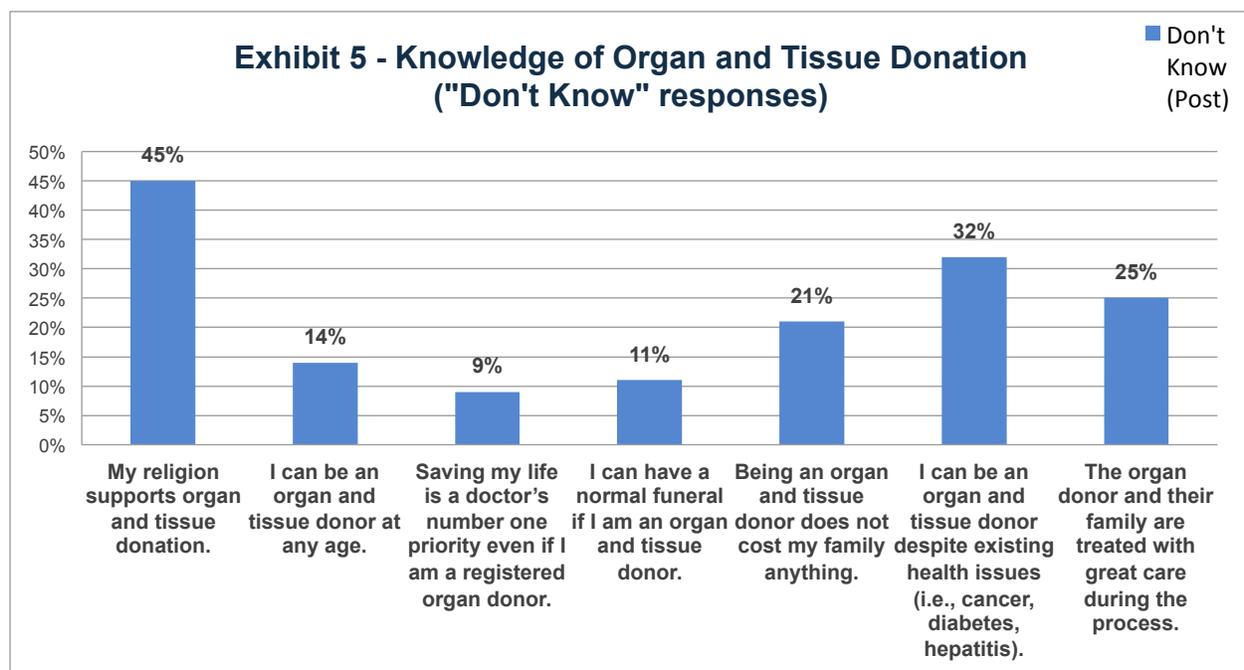


## Ongoing education is needed to debunk myths surrounding donation

Although there was some fluctuation in the belief in myths surrounding donation pre and post surveys, it was not remarkable. 45 percent of respondents still do not know if their religion supports donation, 32 percent do not know if they can be a donor in spite of existing health conditions and 21 percent don't know if being a donor would cost their family money. Details on donation beliefs in Exhibits 4 and 5 below.

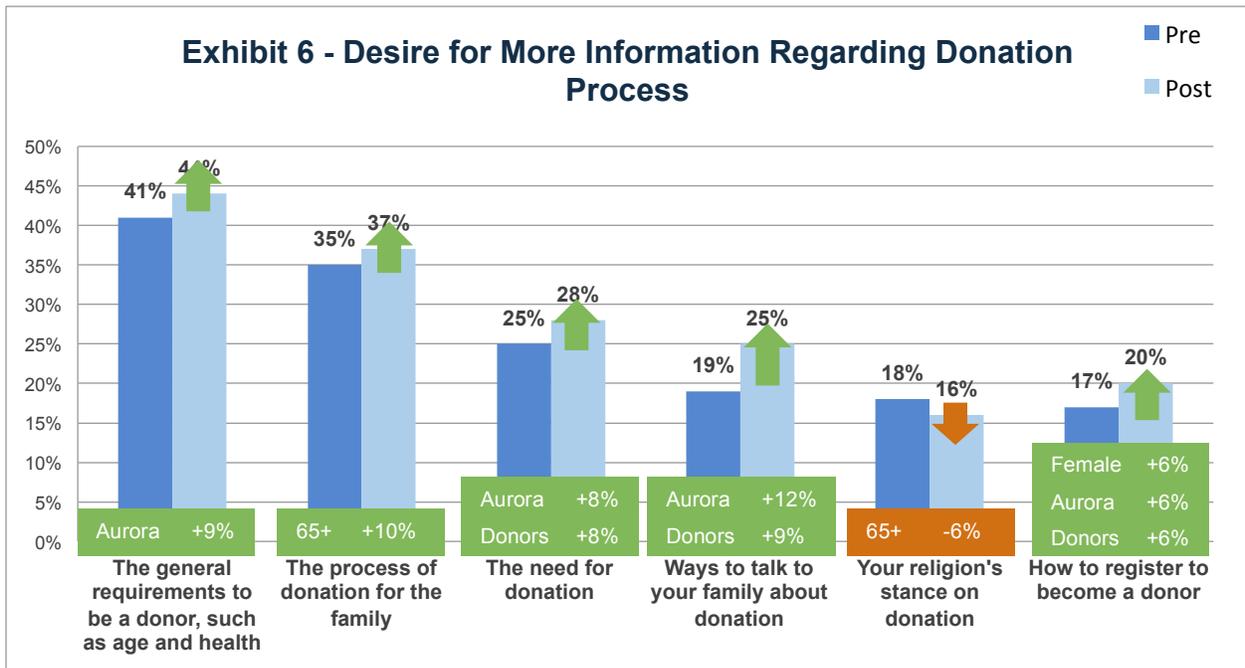


Respondents were asked their level of agreement with various statements regarding organ and tissue donation. Shown above are percentages of respondents indicating that they "Strongly" or "Somewhat" agree with the statements on both the pre and post surveys. Shown below are the proportion of respondents indicating that they "don't know" in the post survey.



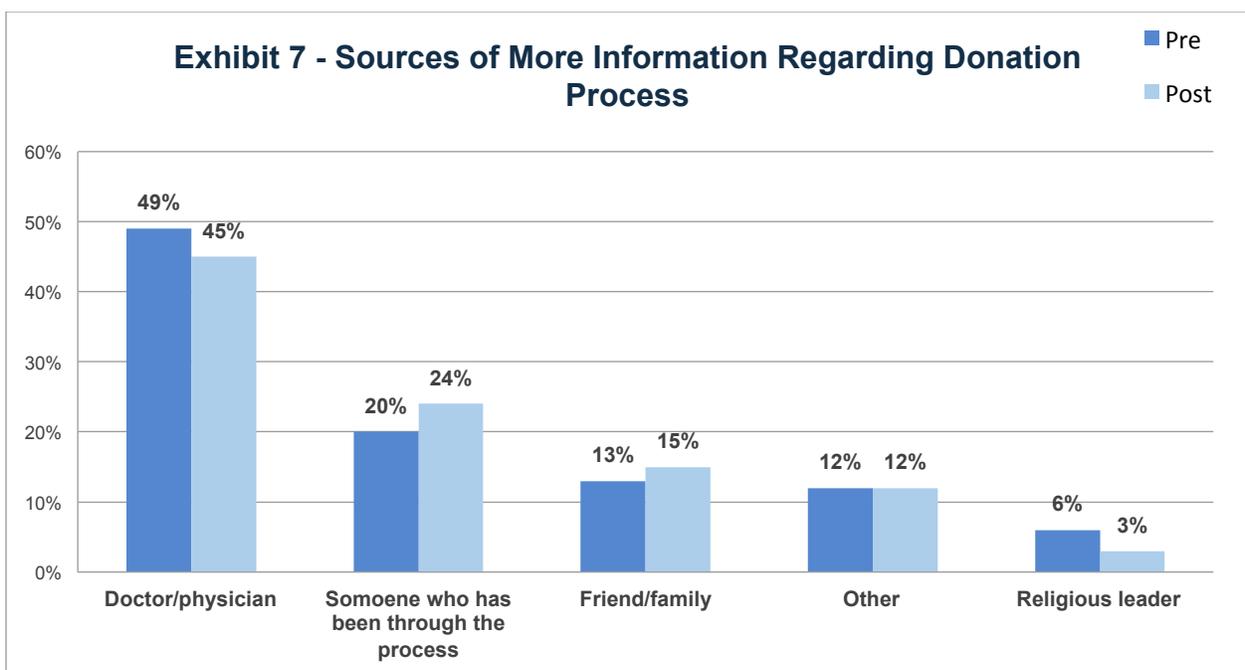
## More information is desired and residents want to make an educated choice

Post survey respondents generally had a higher level of interest in receiving additional information about various aspects of the organ and tissue donation process, as shown in Exhibit 6.



## Residents are most comfortable receiving additional information about donation from their doctors

When asked from which sources they would feel most comfortable receiving additional information regarding the organ and tissue donation process, both pre and post survey respondents indicated being most likely to want to hear more information from a doctor or physician, followed by “someone who has been through the process,” as indicated in Exhibit 7 below.



## KEY LEARNINGS AND RECOMMENDATIONS

Most importantly, pre and post community campaign surveys demonstrated that targeted education and awareness-building activities leads to an increased registration of organ, eye and tissue donors in areas of lower donor designation. It is our chief recommendation that organ procurement organizations and affiliated businesses and groups interested in boosting designation rates in lower performing areas continue to focus consistent education efforts in these communities.

Also, many people in the geographic areas studied continue to believe myths surrounding organ, eye and tissue donation. A limited community campaign is not enough to fully educate and change untrue beliefs. Unfortunately myths about donation have become entrenched with some residents and broad, ongoing education is needed to correct this. For this reason, it is advisable for organ procurement organizations and others to continue to provide consistent education on the truths of donation to encourage lower performing communities not to let myths stand in the way of saving lives. Specifically, residents must be educated that:

- All major religions in the United States support organ, eye and tissue donation and see it as the final act of love and generosity toward others.
- Anyone can register to be a donor, regardless of age, race, or medical history.
- The first priority of any medical professional is to save lives when sick or injured people come to the hospital. Organ and tissue donation does not become an option until death has been declared.
- An open casket funeral is possible for organ, eye and tissue donors.
- There is no cost to the donor or their family for organ, eye or tissue donation.
- Throughout the entire donation process the donor's body is treated with care, respect and dignity.

Doctors and other medical professionals were the most common source that respondents would feel comfortable receiving more information from regarding organ and tissue donation. Efforts to arm these professionals with educational information about donation and talking points to address the topic with their patients would be helpful. Additionally, the second most preferred source was “someone who has experienced a transplant or donation.” As such, we encourage donation and transplant organizations to share testimonials and case studies of organ, eye and tissue recipients as well as donor families through myriad avenues (i.e. website, advertising, media, social media, educational outreach, etc.)

Finally, the community campaign was effective in increasing conversations about donation, particularly among non-donors. Because of this, education and communications from donation organizations should be tailored to provide tools to aid families in starting and having conversations on the topic.

## APPENDIX

### Survey Methodology

The surveys on which this report is based were conducted independently by research firm Corona Insights.

A total of 4,000 surveys were mailed to all three areas during the first wave, with an additional 4,000 mailed in the second wave. All surveys were collected via mail. To select recipients, a random sample was drawn from a list of USPS addresses in proportion to each targeted area. Different addresses were used for each survey wave to reduce the chance of the pre survey impacting awareness. A cover letter in both English and Spanish was provided explaining the importance of the study and a pre-addressed and stamped envelope was included with each survey for return to Corona Insights.

As an incentive for completing the survey, respondents were entered in a drawing to win one of five store gift cards in the amount of \$100. A prize drawing entry slip was included with each survey. This prize slip was separated from the survey once returned to ensure anonymity of the respondent.

The pre survey was conducted between June 30th and July 15th, 2011. The post survey was conducted between January 5th and February 7th, 2012.

To ensure that the findings were as representative as possible of the total population in the study areas, Corona applied corrective weightings. The age and gender of respondents were compared to the known distribution of ages and genders in the three targeted geographies (identified ZIP codes within Denver, Aurora, and Pueblo). This comparison revealed that the survey had a disproportionately high level of females and older respondents, which is typical in a public survey of this type. For that reason, males and younger respondents were weighted more heavily in our analysis than females and older respondents.

In total, 308 pre and 306 post surveys were completed (8 percent response rate). This response level is sufficient to achieve a maximum margin of sampling error of  $\pm 11$  percent at the 95 percent confidence level.

## **About Donor Alliance**

Donor Alliance is the federally-designated, non-profit organ procurement organization and an American Association of Tissue Banks (AATB) accredited tissue bank serving Colorado and most of Wyoming. As a recognized leader in facilitating the donation and recovery of transplantable organs and tissues, Donor Alliance's mission is to save lives through organ and tissue donation and transplantation. To achieve this mission, Donor Alliance employs an effective family approach and recovery programs in more than 100 hospitals. Donor Alliance also inspires the public to register as organ and tissue donors through community partnerships, public outreach and educational campaigns throughout its donation service area.

## **About Andrea Smith**

Andrea Smith is the director of communications/PR at Donor Alliance, the federally designated organ procurement organization for Colorado and most of Wyoming. Smith works to educate and inspire the public to register as organ and tissue donors through the design and implementation of marketing communication, community relations and related public education programs.