



AzMN's Tissue Donor Awareness Program (TDAP™) Overview

**For Additional Agendas or Details about the
TDAP Program Contact Barbara Kavanagh at
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Embracing Change: Clinical Research in the 21st Century

AzMN: Part of the TEAM!

- Why don't patients participate in research?
- Why are there so few clinical trials in the U.S.?
- Why are there so few from underserved and/or culturally diverse populations?

What do we need to do to change this?

- The role of the cancer patient
- The role of the cancer caregiver
- The role of the research advocate
- The role of the medical/science/business community

Awareness· Education· Collaboration· Commitment

We are all on the same TEAM!

TDAPTM Program Model

Sample Agenda

The TDAP program brings together a panel of researchers, community healthcare professionals, cancer patient and clinical trial participant and caregiver. The three hour program is free, open to the public, and provides informational materials and resources for all attendees.

- What are *biospecimens* and what do they have to do with *tissue*?
- How are they used in research?
- What myths persist about tissue donation?
- Why is DNA and genetic research important?
- Why does genetic research need so many biospecimen samples?
- What is the difference between donation and a clinical trial?
- How are my samples kept confidential?
- What do I need to know and do to donate?
- What Arizona resources are available to help me?

Players in the Donation Process

- **Patients** for donation and participants in clinical trials
- **Doctors** who identify patients
- **Coordinators** who consent patients
- **Surgeons & nurses** who handle the tissue
- **Pathologists** who make diagnoses
- **Coordinators** who process, store and ship samples
- **Investigators** who receive and analyze the samples
- **Internal review boards and lawyers** who scrutinize the process and protect the rights and confidentiality of patients and study participants
- **Administrators & coordinators** who track clinical and legal information, using both paper and electronic methods

What Do I Need To Know And Do To Donate?

- ***Understand your rights and protections*** regarding your samples
- ***Ask your doctor(s) to collect a biospecimen*** for research before any surgical procedure
- ***Make sure your surgeon is made aware of local biospecimen resources*** to help with getting the samples
- ***Look for clinical trials online*** that are similar to your condition or disease that collect samples

Why Don't People Donate?

- Religious and Cultural Reasons
- Privacy Concerns
- Insurance
- Employment
- Misconceptions (“Can they clone me?”)

It is your right to refuse to donate.

No means no.

You don't have to give a reason.