

History of the Early and Long Contact Model

(Revised for the U.S. 5/2017)

Mid to Late 1970s

Procurement coordinators work directly for kidney transplant surgeons. There is a moratorium on heart transplantation and the only tissues transplanted outside of Navy facilities are corneas. Most coordinators are professionally trained as renal technicians, PAs, or nurses. There is usually only one kidney program in a city or state, so the coordinators are based in the single hospital in which the surgeon performs transplants. **All coordinators are what we today call In-House or Embedded Coordinators.**

Early coordinators locate prospective donors by visiting ICUs, searching for patients with irreversible brain injuries. Brain death is rarely tested for, so it is not unusual for coordinators to visit the families of vented patients with brain injuries in ICU waiting rooms, offer help and assistance, facilitate out-of-hours visits with patients, and generally establish rapport. Once trust is established, the subject of donation is broached. **(This is today called the Early and Long Contact Model.)** If a family appears receptive, behind the scenes the subject of brain death testing is approached with the neurosurgeon. Doctors and ICU nurses do not see identifying donors and facilitating donation as a legitimate activity for anybody and they throw up roadblocks. Many bodies are left on vents until their hearts stop and their fingers rot, even if families agree to donation.

Coordinators who are effective have extremely good interpersonal skills and know how to get around barriers, make friends, and establish rapport with families. (Many of these people eventually become leaders in OPOs and reintroduce the In-House Coordinator model in the U.S. two decades later.) Other less effective coordinators just wait around for families to bring up the subject of donation to somebody on the unit and then talk to them. **The**

success of the individual program rests almost exclusively on the pro-activity and interpersonal skills of the coordinator.

In the mid to late 1970s, the procurement system is ineffective in several respects:

1. Death rates of people needing transplants are high and the list growing;
2. Few families are approached for donation, as hospital staff negotiate among themselves about which families look like they might be receptive and which neurosurgeons might tolerate interference;
3. Families of patients who die outside of transplant centers are approached for donation only if they insist;
4. Families endure prolonged stays in the hospital watching over dead bodies waiting for heart stoppages;
5. ICU beds are taken up by the dead;
6. Insurance companies begin questioning charges incurred for dead people;
7. The U.S. Government, which finances the End Stage Renal Disease Program, is paying more per patient for dialysis than for kidney transplants.

Going forward, changes in the U.S. procurement system address these problems and are initiated in consultation with procurement professionals. But the real movers are the U.S. Government, big pharmaceutical companies, and insurers, and progress is driven by the discovery of more effective immunosuppressants, research into donation, and a growing awareness, both within the healthcare establishment and out, of the unnecessary loss of life and of waste of healthcare dollars produced by an ineffective system.

1976	First annual meeting of transplant coordinators in U.S.
1978	First clinical use of Cyclosporine in trials in Cambridge, England.

- 1980** The neurological criteria for determination of brain death in the U.S. (Harvard Criteria, 1968) leads to the **slow** establishment, state by state, of the Uniform Determination of Death Act.
- 1982** When Margaret Verble and Judy Worth make a presentation on skills for approaching families to request organ donation at the 6th Annual NATCO meeting in San Antonio, many coordinators in the audience argue that approaching for donation, rather than waiting to see if the family brings the subject up, is unethical. A vigorous debate ensues.
- 1983** Cyclosporine is approved for use in the U.S.
- The Sandoz Pharmaceutical Company (which will hold the patent on Cyclosporine) gives the first award for achievement in organ procurement.
- First multi-organ transplants are done in the U.S.
- 1985** The U.S. Government devotes \$25,000,000 to funding OPOs. This begins the movement of OPOs out of hospitals and starts addressing problems listed above.
- 1986** The Required Request law is passed, requiring all hospitals to establish protocols for offering all families of patients with poor prognoses the option of donation.
- The OPO Consolidation and Service Area Designation Act regulates OPOs for the first time. Many merge and locate outside of hospitals. The **Short Contact Model (rushing to hospitals to talk to families)** becomes the established norm because most OPOs are now stand-alone organizations and all serve many hospitals.
- 1988** Medicare Conditions of Participation state that all hospitals must refer all deaths to their designated OPO. Donor rates jump 4.8%.
- 1991** Poorly designed “de-coupling” research published in *Surgery, Gynecology and Obstetrics* finds that when the brain death conversation is separated from the donation conversation donation rates significantly increase. This

research is used to exclude physicians and nurses from donation conversations and to promote the role of the coordinator.

1993 Approximately 2000 transplant coordinators are employed in the U.S.

The Coalition for Organ Donation starts the “Share Your Life, Share Your Decision” ad campaign. Money begins to pour into public education as a way to get more donors.

1995 The National Organ and Tissue Procurement Study promotes public education, signing donor registries, and sharing decisions as the path to more donations.

Late 1990s Both published research and comparative statistics kept on OPO performance begin to demonstrate that there are best practices in organ donation that make significant differences in numbers of donors. These practices include: early referral of all potential donors; **the presence of donation personnel on units before death for assessment, coordination, and contact with families; ownership and accountability for hospitals and their personnel.**

1998 The U.S. toughens the 1988 Conditions of Participation with more stringent criteria and requires Routine Notification of all ICU deaths to the appropriate OPO, regardless of assumptions about eligibility.

2002 Sade publishes research showing a doubling of consent rates implementing an **Early and Long Contact Model** with families in S.C. Other studies by Dickerson and Shafer demonstrate that in-house coordinators who have time to establish early rapport with families have unusually high consent rates, and that when coordinators are with doctors during BD conversations consent rates double.

However, since the mid-1990’s, nation-wide donor numbers grow on the average of only 2% per year. And best practices identified in the research are not routinely implemented for a variety of reasons. Those include the lack of adequate OPO staffing, competition among OPOs, a lack of avenues to share information, a disconnect

between “hospital development” and requestor personnel in OPOs, the resentment of hospital personnel who have been pushed to the side by members of the new coordinator profession, and inexperience in approaching families of non-heart beating potential donors (DCDs).

2003

Based on the research mentioned above, the Breakthrough Collaborative on Organ Donation is launched by the U.S. Government to address the lack of best practices by most OPOs. This initiative focuses on what happens in hospitals -- identifying potential donors, early referral, and early contact
- and on expanding the donor pool with DCDs. In the next two years, there is a 19% increase in donors.

2007

The Collaborative ends with donors up 13% over the first full year of the initiative. DCD donors have increased by 216% and have become embedded (in much of the country) as a new type of donor.

2008 - 2013

While donor registry numbers soar, actual donors flatline.

2014 - 2017

The opioid crisis strikes the white, middle class. Donors rise.

DCD donors represent the best opportunities for donor growth, but at some OPOS up to 20% of families of registered DCD donors refuse donation, and many other families want to “withdraw immediately.”

Coordinators, who are often called in too late, huddle with doctors and nurses to get information, but contrary to best practices identified in the research a decade before, still often approach on their own and have to ask for donations before establishing rapport with families.

Money continues to pour into public education, registries, and studies on strategies to get people to sign up, although no research to date has found registries to be effective in actually raising donor numbers.