# What Did You Need? My Kid's Knees?!

How To Do Donor Outreach When No One Offers Voluntarily

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### Concept Inception

Realized the need during pre-transplant psychosocial assessments

Initial discussion of outreach with recipients

What I noted after follow-up with recipients

#### Barriers to Overcome

 How do I ask someone to give me their kidney?

Concern for their donor's future health

 My family and friends already know about my situation so they would have offered if they wanted to

#### The Donor Outreach Letter

 Less a plea for help with donating, but more an informational letter stating a patient's current situation

 It addresses the patient's concern and does not come off as "Can you give me your kidney?"

## Engaging patients about the idea of outreach

Hopefully done in pre-dialysis stage

Can be done by RN or SW

Obviously something we can't force a patient to do

 Example of parents asking for a bone marrow donor for a child.

- Outreach should be directed to people they know: family, friends, work colleagues, church members.
- Risks of outreaching to people you don't know
- Lastly, emotional impacts of doing such an undertaking and not yielding any donors.

### Living Donor Kidney Transplants in SPH since 2007, by Relationship of Donor to Recipient

RELATION	2007	2008	2009	2010	2011	Total
Living Biologically Unrelated	13	12	13	22	11	71
Offspring	6	2	6	7	6	27
Other Biologically Related	3	1	1	3	3	11
Parent	7	5	3	5	3	23
Sibling	14	18	8	12	9	61
Spouse	8	9	14	5	8	44
Total	51	47	45	54	40	237

### Outreach Letter Specifics

Opening salutation of the letter states
 "Dear Family and Friends." Does not say,
 "Dear Elizabeth or Dear Neal"

 Informs the recipient of the fact that dialysis does not completely replace a normal kidney's function

- Informs their family and friends about the patient's current health, their suitability for a transplant and the fact that the medical team recommends transplant as a treatment option
- Discusses the patient's option to wait for a kidney from a deceased donor
- For patients on dialysis, a description of what that experience is like for them

- Relay how ESRD or being on dialysis has impacted their quality of life
  - Can't go swimming
  - Have to go to H.D. 3x a week
  - Have to be home at a certain time to hook-up
    P.D. cycler
  - Can't work full-time or not at all
  - Less time with my children
  - Affects ease of travel

 States that they do not need to hear back from the prospective donor. They can contact donor team directly and even work up anonymously.

 Gives the prospective donor an out. "If this is not for you, then your support is enough and this will not affect our relationship."  Provides email and phone number of donor RN to begin the process

Included is a link to BC Transplant's FAQ about living donation

## Key information for recipients about donor outreach

- Donor approval process
- Google result "Kidney Donors Live Longer."
- Prevalence of the population developing kidney disease and going on to dialysis or transplantation = <1%</li>
- If a donor somehow ends up with kidney failure and needs a transplant themselves, if they have no living donor, they go to the top of the waiting list.

#### Results Noted

Social work donor questionnaire responses

 Sister who donated after receiving the outreach letter

### What may not be helpful

Self-screening the donors

Offers of payment or compensation

Undue pressure

Overcontrolling the situation

## Other Considerations For Donor Outreach

- The concept of a Donor Champion
- Homevisit by RN and SW to do education about living donation to patient and their family and friends
- Education sessions presented by the transplant team.
- Social Media such as Facebook

 "The more you learn, the more you realize how feasible it is. It's like someone dying of thirst and you're sitting there with two glasses of water." – Ricky Cisco, 25y from Royal Oak, Michigan