Implementing HOPE: HIV-positive Living Kidney Donation

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Objectives

▪ Identify the legal and medical regulations by which a PLHIV could donate
▪ Determine operational changes required within our Center to ensure success
▪ Analyze medical differences which need to be considered for a PLHIV Donor
▪ Understand the psychosocial aspects of living donation from a PLHIV
HOPE Act

- HIV Organ Policy Equity Act was enacted on November 21, 2013
- People Living with HIV (PLHIV) Organ Donation allowed under the HOPE Act since 2015
Critical Questions

- What are the *legal and medical regulations* by which PLHIV could donate?

- What *operational* changes are required within our Center to ensure success?

- What *medical differences* should be considered for an HIV+ Living Donor?
Donation Regulations:

What are the Legal and Medical requirements for PLHIV to become living donors?

- NC Health Code changed
  - Changes to legalize HOPE Act in state, prospectively allowed deceased and living donation.

- NIH medical stipulations:
  - Well controlled HIV ≥ 6 months
  - No invasive opportunistic infections or malignancies
  - Pre-implant biopsy
  - Outcome measures
  - Independent advocates
  - Complete HIV history
Operational:

What Operational Changes are Required Within Our Center to Ensure Success?

- Current process
- HOPE Act Donor additional process
- How to incorporate new requirements to existing process?
Evaluation Process

1. Initial contact from patient
2. Episode created with review of PMH
3. Two day evaluation
4. Data gathered for MDC presentation
5. MDC review
6. Candidacy decision
7. Match meeting
8. LD surgery with final tests scheduled
Evaluation Process

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ID history gathered
- Evaluation with HIV provider and HIV independent advocate
- Consult between HIV provider and Renal Medical Director
- HIV team attends MDC
- HOPE consent completed
- Kidney biopsy

CD4 count, HIV viral load and Archive genotype assay
HLA-B5701, HHV8 serology
History: CD4 nadir, OI’s, malignancy and antiviral history
Medical Differences:

What medical differences should be considered for an HIV+ Living Donor?

- Optimization of anti-retroviral therapy
- Earlier administration of medication upon HIV diagnosis
- Modeling of future ESRD risk
  - Additional challenges with HIV
Figure 1. Progression of renal impairment on previous therapies.
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- Patient awaiting further evaluation
- Patients (2) chose to end evaluation
- Medically terminated - Melanoma discovered
- Psychosocial and Medical Concerns
- Patient Donated
Why are we still talking about this?

May 21, 2020:
OPTN Hope Act Variance expanded to include:

Programs that meet necessary research and experience requirements to recover and transplant all solid organs
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Source: Organ Procurement and Transplantation Network (OPTN)
Lessons Learned and Future Direction

- Much to be learned about HIV+ LD kidney prognosis
- Future research to focus on education into HIV+ community, donor selection, and transplant outcomes
- Future research regarding ethnicity of PLHIV donors and HIV + Candidates.
- Future virology research looking at donor and recipient viral evolution, reservoir formation and quasi-species generation in the renal tubular epithelium
- What can you do?
Keep Talking

The first HIV+ living kidney donor at Duke (second in the US) donated in August 2019
Understand the psychosocial aspects of living donation from a PLHIV
Early Personal Story

- Grew up in the suburbs and attended Catholic schools for 12 years
- “Came out” in 5th grade
- In 1981 I was heading to high school and HIV was just a blip in the media in larger cities
- By 1984 I was planning my college future and looked at Boston as a city.
- The 80’s were crazy and depressing!
- Burnout after 4 years and moved back home
“Adulthood”

- 1990’s: Moved back home and met my future husband Larry
- Relocated to Washington, DC in 1991 and later Hampton Roads
- HIV changed: Meds became effective and resource focus changed
- Grassroots equality rights from the foundations of HIV movement: visitation rights, entitlement to death benefits, marriage, workplace protection
- By 1995 I had graduated nursing school and by 2000 was continuing as a transplant nurse in the coordinator role
Diagnosis

- After 19 years Larry and I separated and I dated for the 1\textsuperscript{st} time in 20 years as a 40 y.o.
- What changed in 2009 from 1989? The internet
- In 2010 I was diagnosed with HIV
- Remember the 5 stages of grief?
  - Denial, anger, bargaining, depression, acceptance
HIV Stigma

- Negative feelings about people living with HIV (PLHIV)
- Initially a universal fear of infection due to lack of knowledge of disease
- After safe sex: stigma of certain sexual practices
- Internet dating. “clean only” “HIV- only”
- Antiretrovirals have made HIV undetectable
- U=U (Undetectable is untransmittable). Stigma gone? No
Road to Donation

- Wanted to donate in my 20-30’s. Not the right time

- In my early 40’s, I became HIV+ and the option was no longer available

- Worked in transplant for 15 years at that time and seeing other donors was positive but difficult. Why did I get infected and they didn’t? Those high risk deceased donors should be positive too

- Congressional discussions started to change laws. Early advocacy and contacting Barbara Boxer

- HOPE Act passes and literally gave me hope for acceptance in donation

- Didn’t think about living donation at that point for myself until Dec 2018
Donation

- State of mind was acceptance at this time. Married to a PLHIV and undetectable

- There were very few people who knew my status. Self stigma?

- Initial meeting: No information available prior to meeting?
  - Nervous and excited.
  - Trailblazing? Wasn’t planning on that

- Caught up in self inflicted maelstrom. Media planning, research, preop calls to family and PR departments…

- Where did my recovery fit into all this?
Post Donation

- I had tremendous support: Husband, family, friends, coordinator and 1st PLHIV donor
- My recovery was allowed for a few weeks then …
  - Back to work
  - Media at 6 weeks for a few months
  - Requests for donation committee work
- How did I feel? Proud and overwhelmed. Role modeling is really difficult
- Then COVID…all consuming and my journey changed.
  - My role became clinical with personal references in committees.
  - Felt selfish to discuss donating life while people were dying
- Present day: Normalcy? Expert without pride? Role model?
  - Constant reminders: speaking requests, impromptu discussions, advocacy
“Like many 20 year old gay men in the 80’s, one of things in the forefront of my mind was staying alive. Now 30 years later as a healthy undetectable HIV + transplant coordinator, I have the ability to help someone else worried about staying alive. Donation was not a difficult decision to make. “

- Karl