



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 *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 \geq 6 months
 - No invasive opportunistic infections or malignancies
 - Pre-implant biopsy
 - Outcome measures
 - Independent advocates
 - Complete HIV history



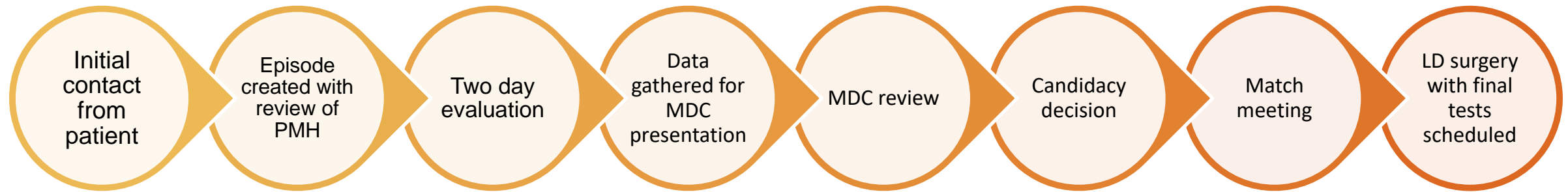
Operational:

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?

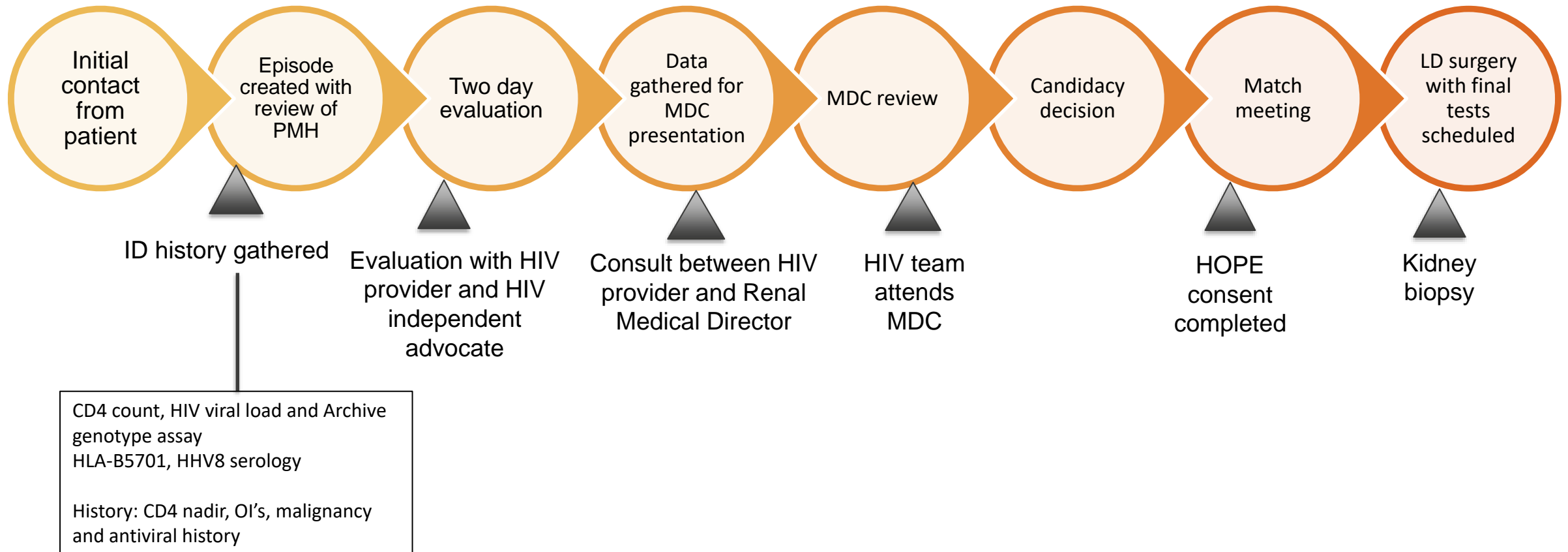


Evaluation Process





Evaluation Process





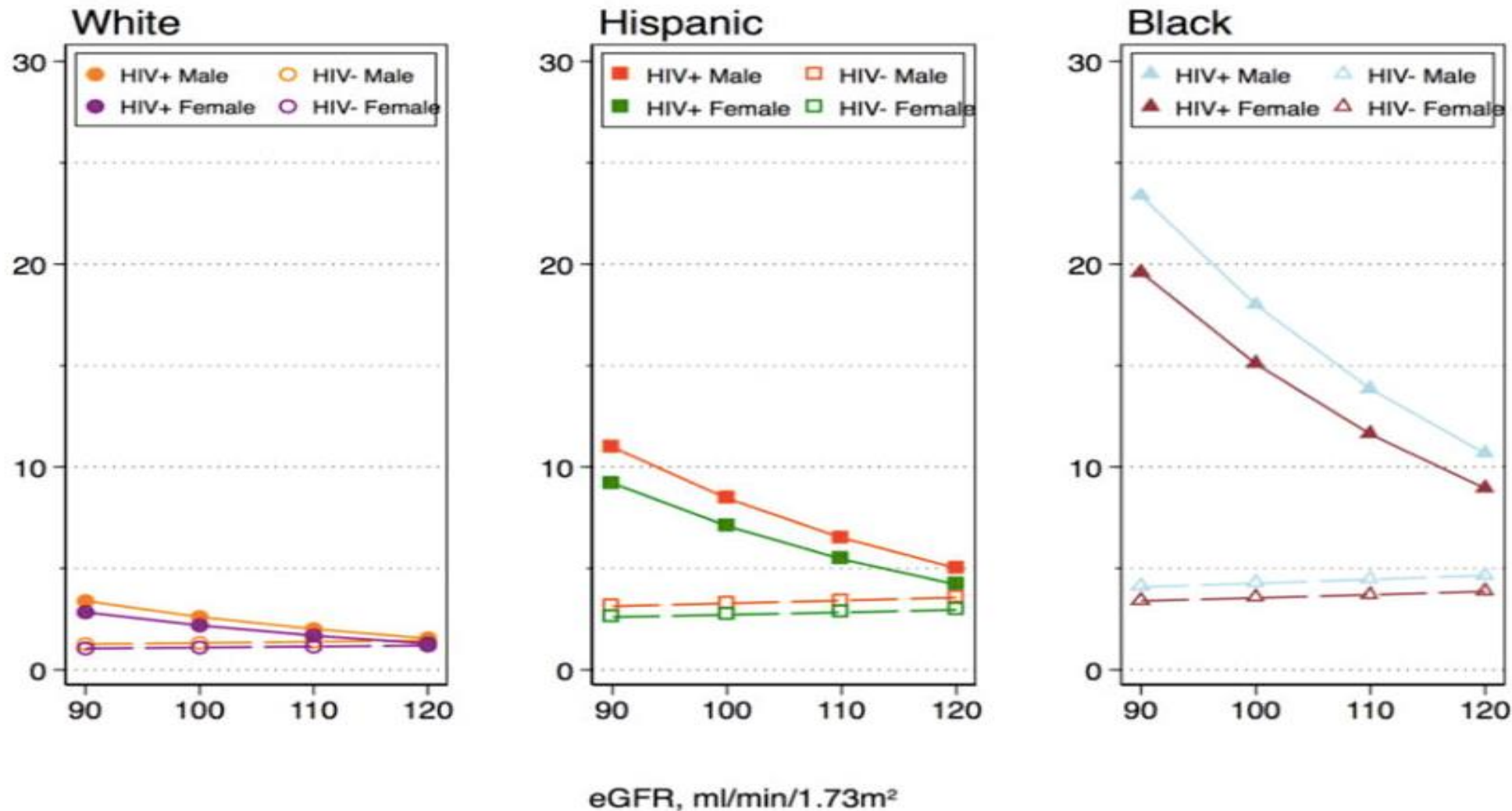
Medical Differences:

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



9-Year Cumulative Incidence, per 10,000

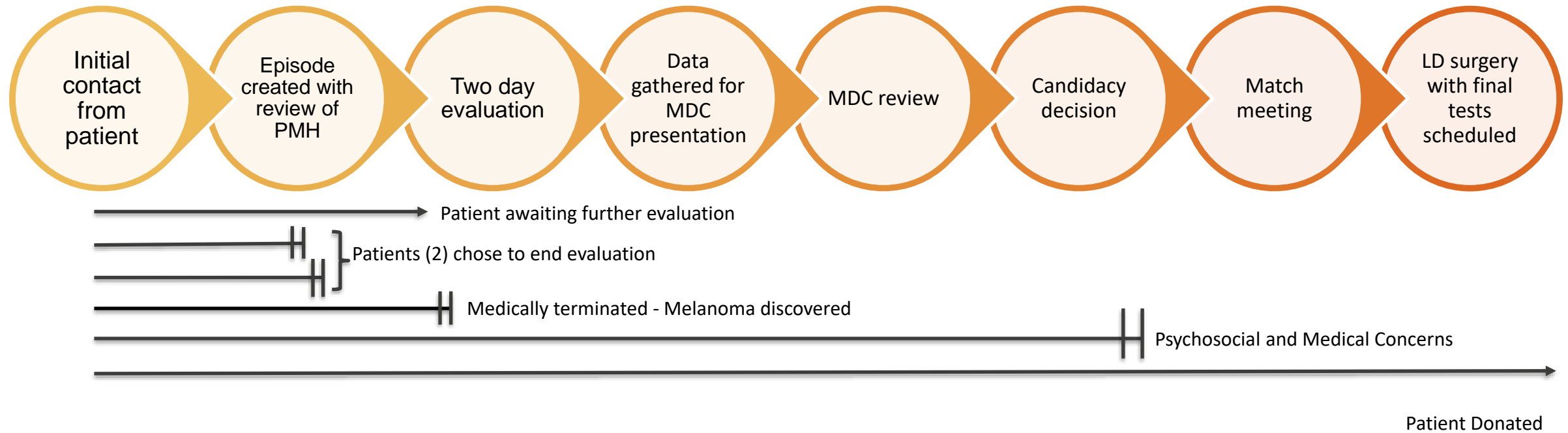


Muzaale, A. D., Althoff, K. N., Sperati, C. J., Abraham, A. G., Kucirka, L. M., Massie, A. B., ... & Silverberg, M. J. (2017). Risk of End-Stage Renal Disease in HIV-Positive Potential Live Kidney Donors. *American Journal of Transplantation*, 17(7), 1823-1832.

Figure 1. progression of renal impairment on previous therapies



Evaluation Process





Why are we still talking about this?



May 21, 2020:

OPTN Hope Act Variance
expanded to include:

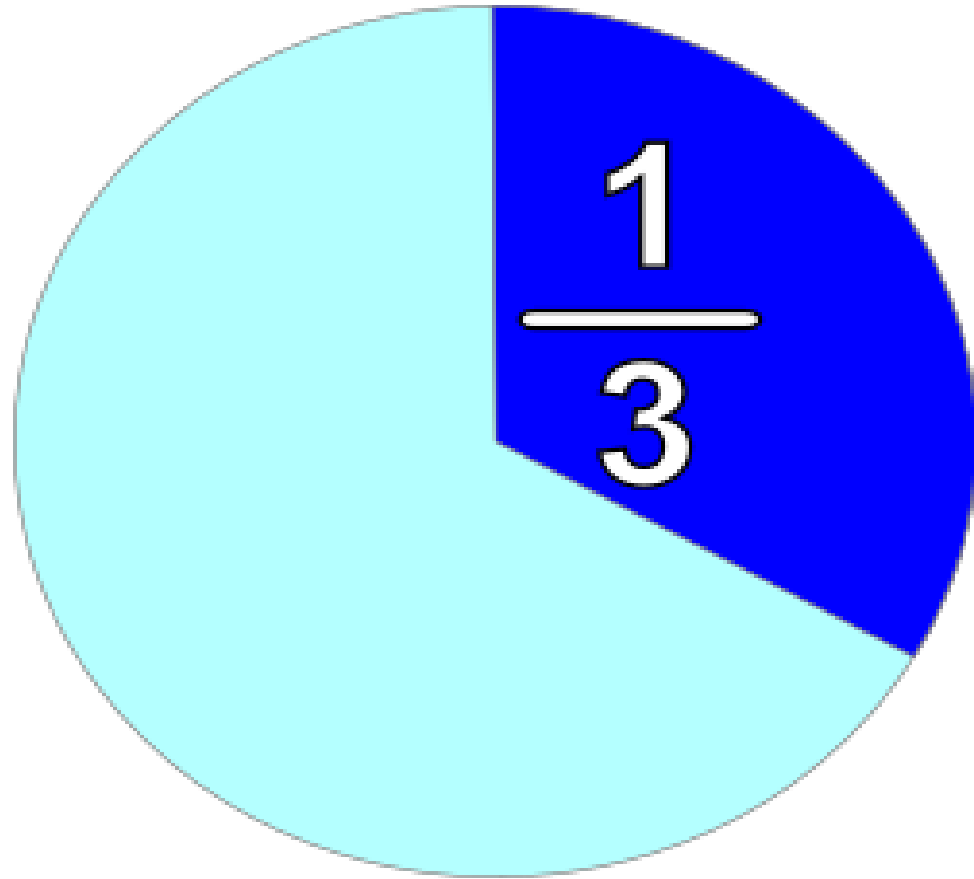
Programs that meet necessary
research and experience
requirements to recover and
transplant all solid organs



March 1, 2022

State	Center Name	Kidney		Liver		Heart
		Deceased Donor	Living Donor	Deceased Donor	Living Donor	Deceased Donor
AL	University of Alabama Hospital	X		X		
AR	University of Arkansas Medical Center					
CA	Univ of CA San Diego Medical Center	X		X		
CA	Univ of CA San Francisco Medical Center	X				
CA	Univ of CA Los Angeles Medical Center	X				
CT	Yale New Haven Hospital	X		X		
DC	Georgetown Univ Medical Center	X		X		
FL	Cleveland Clinic Florida Weston	X				
FL	Jackson Memorial Hospital	X		X		
GA	Emory University Hospital	X		X		
IL	Northwestern Memorial Hospital	X	X	X		
IL	Rush University Medical Center	X		X		
IN	Indiana University Health	X		X		
LA	Ochsner Foundation Hospital	X		X		
LA	Tulane Medical Center	X	X			
MA	Massachusetts General Hospital	X		X		
MD	Johns Hopkins Hospital	X	X	X		
MD	University of Maryland Medical System	X		X		
MN	University of Minnesota Medical Center	X		X	X	
NC	Duke University Hospital	X	X	X	X	
NJ	Saint Barnabas Medical Center	X				
NY	Montefiore Medical Center	X				
NY	Mount Sinai Medical Center	X	X	X		
NY	New York-Presbyterian/Columbia	X				X
NY	New York-Presbyterian/Weill Cornell	X		X		
NY	New York University Medical Center	X	X			
OH	The Cleveland Clinic					
OH	University of Cincinnati Medical Center	X		X		
PA	University of Pittsburgh Medical Center	X		X		
PA	The Hospital of the University of Pennsylvania	X		X		
TN	Methodist University Hospital			X		
TX	UT Southwestern Medical Center/William P. Clements Jr. University Hospital	X		X		
VA	VCU Medical Center	X				
VA	University of Virginia Medical Center	X				

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





Brief History Lesson

HIV/AIDS Timeline

RARE CANCER SEEN IN 41 HOMOSEXUALS

Outbreak Occurs Among Men
in New York and California
—8 Died Inside 2 Years

The New York
Times reports
a mysterious
illness

1981

1982

The name “AIDS”
– Acquired
Immune
Deficiency
Syndrome – is
created

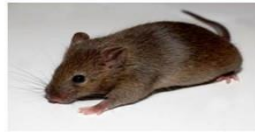


Françoise Barré-
Sinoussi and Luc
Montagnier discover
HIV as the cause of
AIDS and later win
the Nobel Prize

1984

1985

A test for screening
blood donations is
developed through
chimpanzee
research



AZT, developed in
mice, becomes
the first drug
approved for
treating AIDS

1987

1990

8 million
people
have HIV



Infant HIV
infections
begin to fall
due to AZT
treatment

1994

1996

Combination
treatment of
antiretrovirals
developed



AIDS-related
deaths fall in
developed
countries due to
combination
treatments

1997

22 million
people have
HIV



After tests in mice
and macaques,
Truvada is shown to
reduce the risk of
HIV infection

2007

33 million
people
have HIV



The majority of
people
worldwide
eligible for
antiretrovirals
are now
receiving them

2012

Antiretrovirals are
shown to reduce the
risk of transmitting
HIV by 96%



Image credits: Trocaire, Gates Foundation, iStock/LordRunar, Harwell



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 1st 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