## Draft Slides for CBC Presentation

#### Agenda:

Description	Slides	Presenter
Who are we	1-2	MS
Why donation is important to CBC		ВН
How donation works		GW
OPO Performance		MS or GW
CBC Actions		MS

# Introduction of Organizations

- AMAT
- AOPO
- LifeLink
- Gift of Hope

Put logos of the 4 organizations on the page, discuss role of each

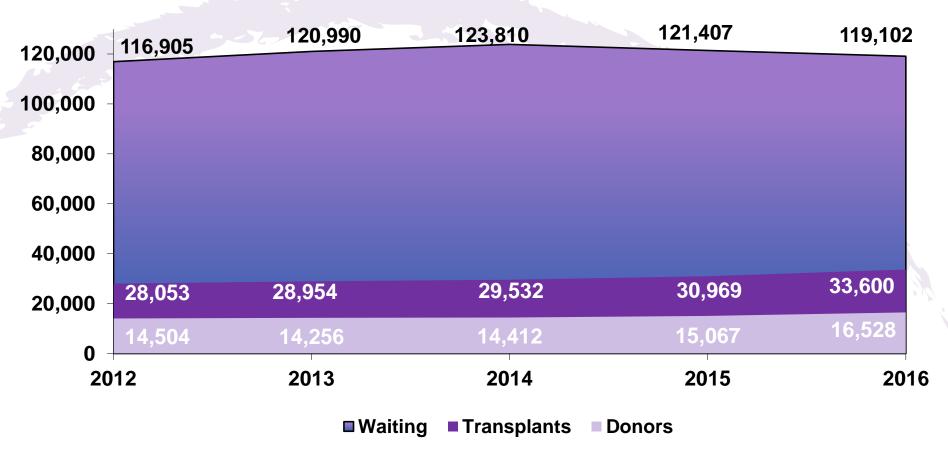
#### **Bobby Howard**

- ➤ President of the NFL Former Players Association, Atlanta Chapter, serves on the board of Donate Life America, and serves as NFL Heads-Up Football Ambassador for youth football.
- Faithfully served in the following capacities:
  - President of the Association for Multicultural Affairs in Transplantation
  - President of the Georgia Transplant Foundation
  - Board member of the United Network of Organ Sharing and board
  - Member of the 100 Black Men of DeKalb County

#### The Need

- Multicultural communities are disproportionately affected by illnesses that can lead to end-stage renal disease (ESRD) and the need for dialysis and/or a kidney transplant.
- > These diseases include, but are not limited to:
  - high blood pressure
  - Diabetes
- ➤ Multicultural patients make up % of the national waiting list
- African Americans make up % of the national wait list for kidneys

#### Thousands Are Waiting change to national graphic



Source: United Network for Organ Sharing



Note: 2016 national Waiting List, Transplants and Donors data is through YE2016. Illinois Waiting List data is through 1/13/17. All data is subject to change based on future data submission or correction.

## Impact on the Black Community

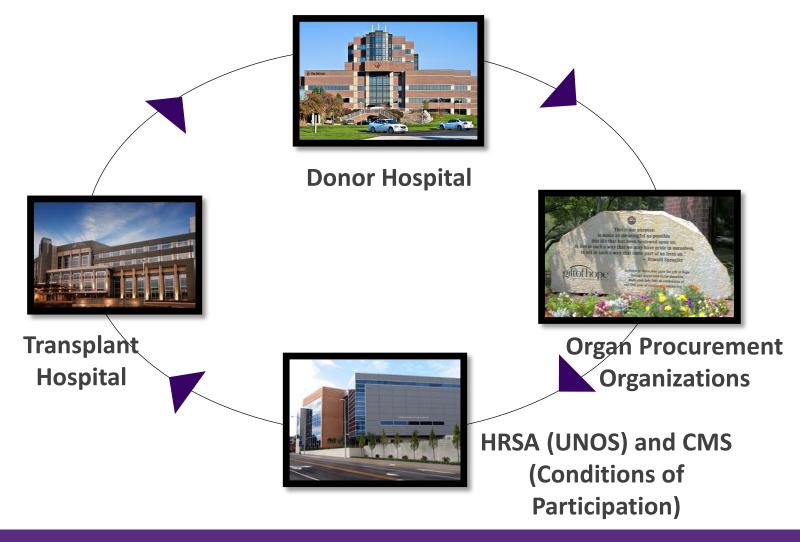
- Use the data below to show need in the black community and current impact on black lives
- Add wait list numbers
- Dialysis population
- Other things we should do to reduce disease healthy lifestyle
- COVID impact

Deceased Kidney Transplants

	2019	2014Increase	
All	16534	11570	43%
Black	5389	3613	49%
% black	33%	31%	

#### Organ Donation Process

#### **The Donation and Transplantation System**





#### **Donation Process**

- > 58 Organ Procurement Organizations
- Around the Country Governed by Organ Procurement and Transplantation Network



#### **Regulation of Organ Donation**

- Center for Medicare & Medicaid Services (CMS)
  - Certifies Organ Procurement Organizations
  - Regulates kidney reimbursement
- Health Resources Services Administration (HRSA)
  - Organ Procurement & Transplantation Network (OPTN)
  - Enforces Organ Recovery and Allocation rules
- FDA
  - Regulates tissue recovery, processing and distribution

Issues: Regulations are not always consistent between agencies and sometimes are detrimental to our mission to Save and Enhance Lives



#### What We Do

Provide compassionate care and support to donors and donor families

Evaluate potential donors for medical suitability

Discuss donation with family members and significant others

Coordinate the organ and tissue recovery process





Provide support and follow-up information to organ & tissue donors families

#### What We Do

Educate the public about donation and how to register as donors

Educate healthcare professionals about their roles in donation





Provide expert and compassionate donation services 24 hours per day

Assist hospitals with the development of policies and procedures that facilitate the donation process

Advocate for best practices in transplantation care

## Organ Donation Performance

- Growth of donation and transplant 2014 to 2019
  - Pull from the data below or other general stats
- Opportunity for improvement in the Black community

Deceased Donors OPTN data 2019				
	2019	2014 increase		
All	11870	8596	38%	
Black	1798	1341	34%	
% black	15%	16%		
Hispanic	1769	1144	55%	
	15%	13%		

#### Improving a high performing system

- US Donation system is the best in the world
  - Add the data
- We must continue to improve as we have over the past decade, especially for our minority communities
  - Donation rates in minority communities lag others
    - Lack of trust in the healthcare system
    - Education in the communities
    - Overall health of the communities

#### **CBC** Actions

- Get know your local OPO:
  - How can your local OPO help you?
  - Use your local OPO for information about donation and transplant for your constituents
- Promote donation within the community
  - National Minority Donation Month Co-sponsor resolution
  - CBC statement of support for donation
  - Support National Education and Registration Efforts
- Regulatory Support
  - Advocate for revised CMS regulations that remove barriers to transplant
  - Federal funding for advance organ preservation and other technologies to improve organ utilization and outcomes

### Areas of Cooperation Between Gift of Hope and Our Congressional Representatives

**Public Education and Promotion of Donation** 

Access to key Regulators and Advocacy for Common Sense Regulatory Reform

Support for Federal Legislation Supportive of Organ Donation and Transplantation



#### **Legislative Support**

#### Join the Congressional Organ & Tissue Donation and Transplantation Awareness Caucus

The **Congressional Organ and Tissue Donation and Transplantation Awareness Caucus** is registered as a Congressional Member Organization for the 115th Congress. This Caucus has been the voice of Congress in promoting organ and tissue donation and transplantation awareness with the goal of encouraging every American citizen to consider being an organ donor. The purpose is to positively impact the rate of life saving organ donation, and lend a national voice to this important issue.

Support the Living Donor Protection Act (H.R. 1270)

Introduced by Rep. Nadler (D-NY) and Rep. Burgess (R-Tx), the **Living Donor Protection Act** promotes organ donation and the rights of living donors. It prohibits insurance companies from denying or limiting life, disability and long term care insurance and from charging higher premiums to living organ donors. Living organ donors may use time granted through the Family and Medical Leave Act (FMLA) to recover from transplant surgery. The Department of Health and Human Services is also directed to add information on these new protections to its materials to encourage more Americans to consider living donation.

Support the Comprehensive Immunosuppressive Drug Coverage for Kidney
Transplant Patients Act

Expected to be introduced later this year, the Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Patients Act will extend Medicare coverage for immunosuppressive medications indefinitely, ensuring patients have access to these lifesaving medications. All other Medicare coverage would end 36 months after the transplant, similar to current law. The bill also requires that group health plans currently providing coverage of immunosuppressive drugs for kidney transplant recipients maintain this coverage.



#### Conclusion

- This is the face of donation and transplant, crossing all social, economic, race and gender boundaries to remind us that we are all part of the human experience
- Add Bobby's story





