

EARLY IDENTIFICATION & INTERVENTION IN CKD

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The Voice of the Patient, Inc.



LEARNING OBJECTIVES

- Patient/Family Perspective: Understanding Our Journey and Narrative
- Patient Engagement: Opportunities and Barriers
- The Business and Moral Case for Early Detection + Intervention of CKD
- The Future of Nephrology

WEST VIRGINIA 1935: OUR FAMILY NARRATIVE

KDIGO



DUVALL FAMILY: ST. LOUIS 1950's



Starting Dialysis: August 1981

- Uncertain Future
- Emotional Impact on Family
- Positive Example
- Fear



October 1981

- 48 Years Old
- Three Children
- Able to Participate in Life
- Unknown Future



May 1983

- Diminished Quality of Life
- Symptoms: Fatigue, Nauseous, Fluid Overload,
- Diminished Ability to Participate in Life
- Uncertain Future
- Hemodialysis Treatment: 50% Mortality at 5 Years



October 2000

- Influence of Family Narrative
- Role of Primary Care Physician
- Limitations of GFR
- Self-Diagnosis
- Self-Referral



Starting a New Narrative

Brent Miller, MD

Professor of Clinical
Medicine

University of Indiana



Catalyst for Patient Engagement

- **Strong Interpersonal Skills**
- **Coach/Teacher**
- **Set High Expectations**
- **Engaged with the End in Mind**

August 2004

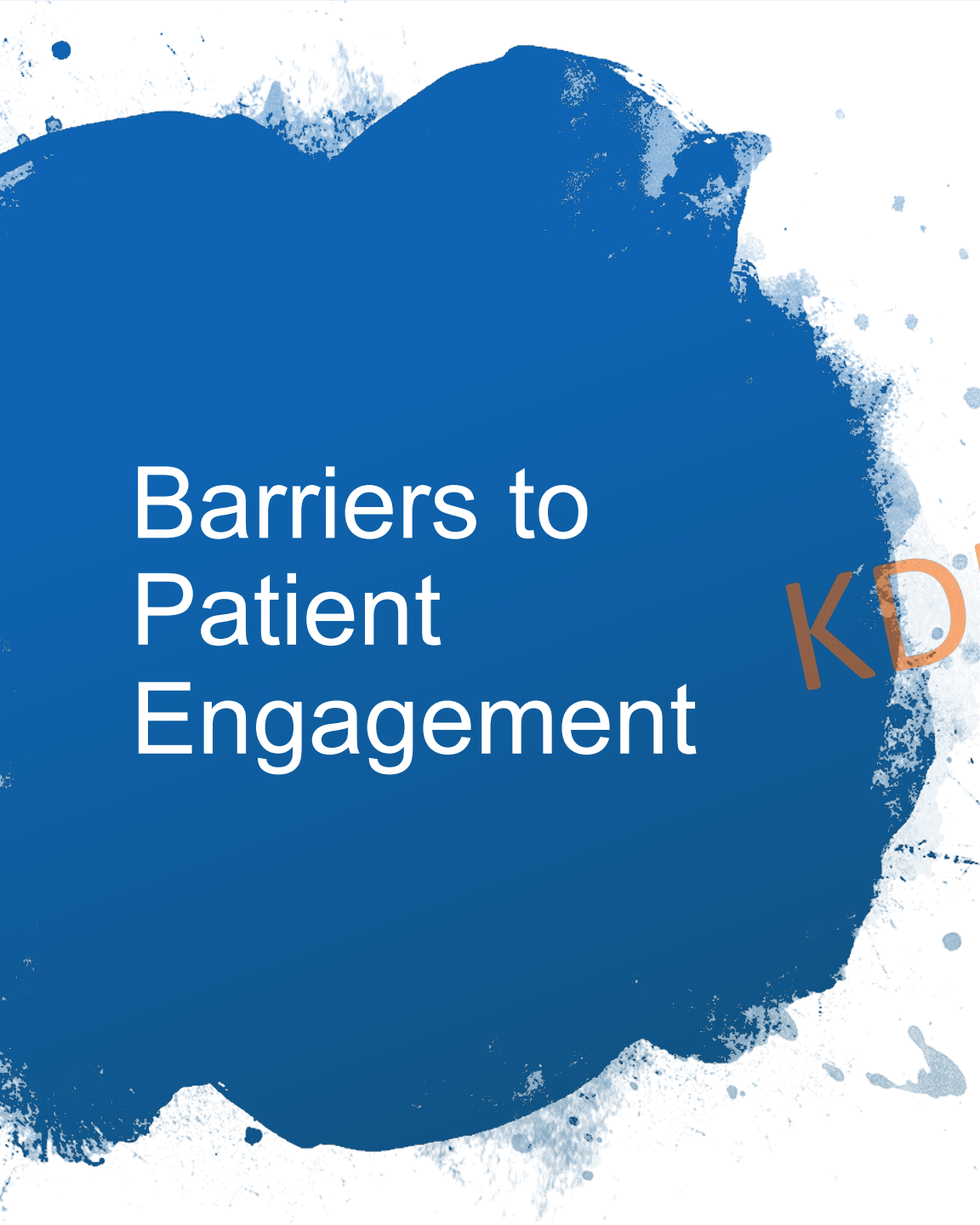
- Detection of PKD: Three Years to Find a Living Donor
- Pre-Emptive Kidney Transplant
- Restoration of my Health
- Returned to Work
- Successfully Rehabilitated



New Life: Gratitude + Managing Risk

- Best Treatment Option, Not a Cure
- Emotional Understanding
- Discipline
- Gaps in Patient Care
- ½ of Kidney Transplants Fail at 10 Years

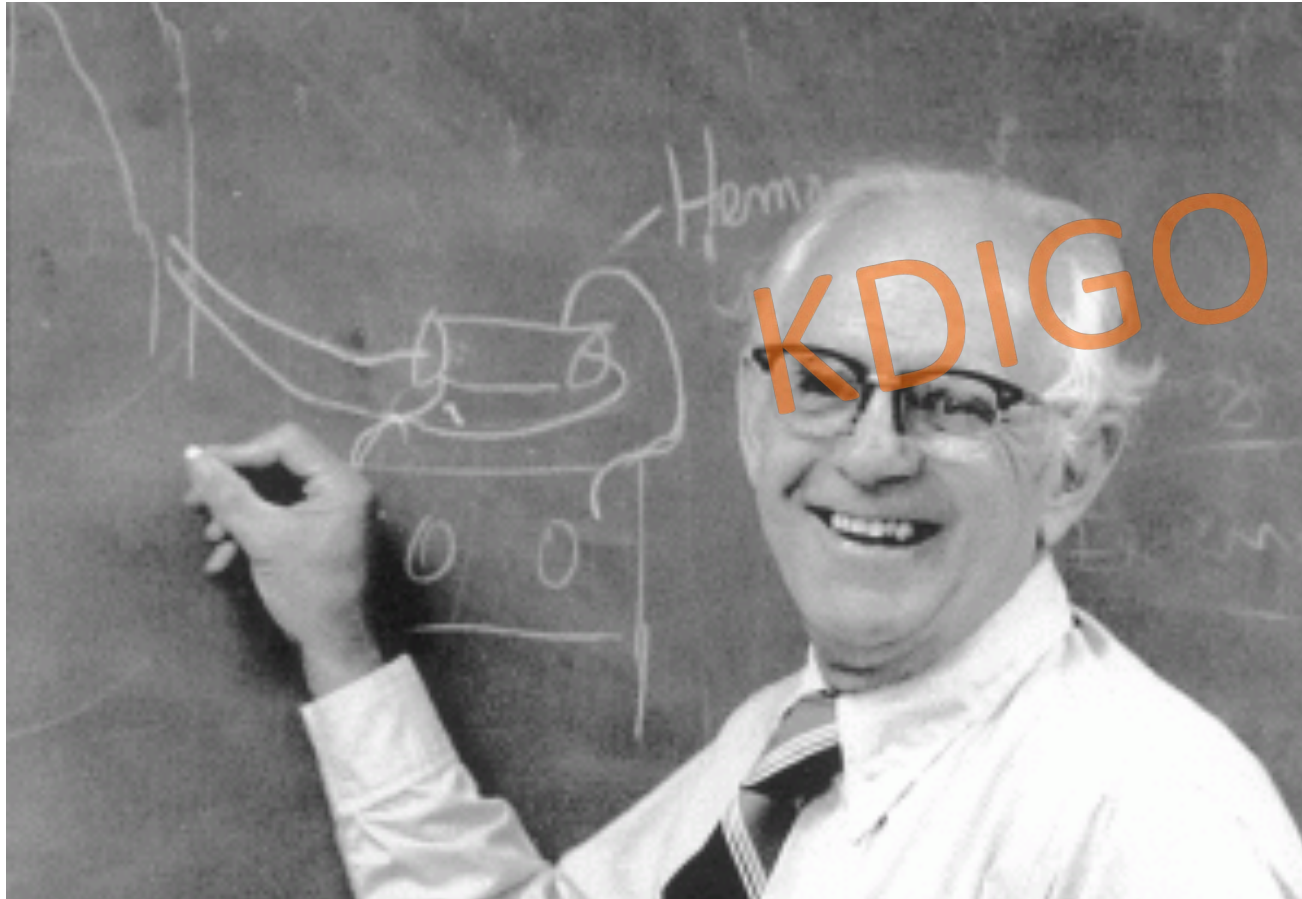


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Barriers to Patient Engagement

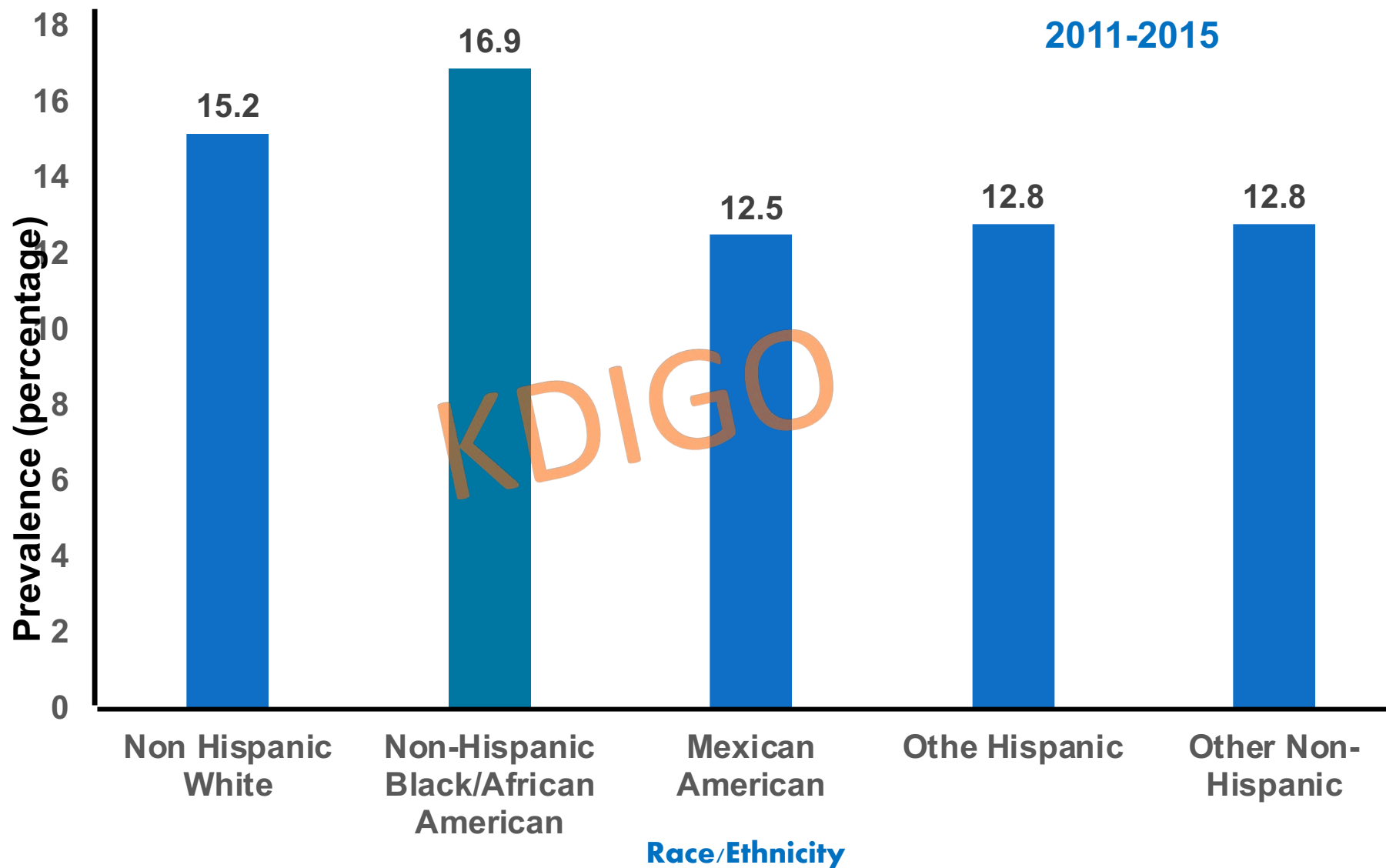
- 
- The KDIGO logo, consisting of the letters 'KDIGO' in a bold, sans-serif font. The 'K' and 'D' are orange, while the 'I', 'G', and 'O' are white with an orange outline.
- System not Serving Kidney Disease Patients
 - Family/Community Narratives on Kidney Disease
 - Large Dialysis Organizations
 - Reimbursement Incentives
 - Low Expectations

Belding Scribner, MD

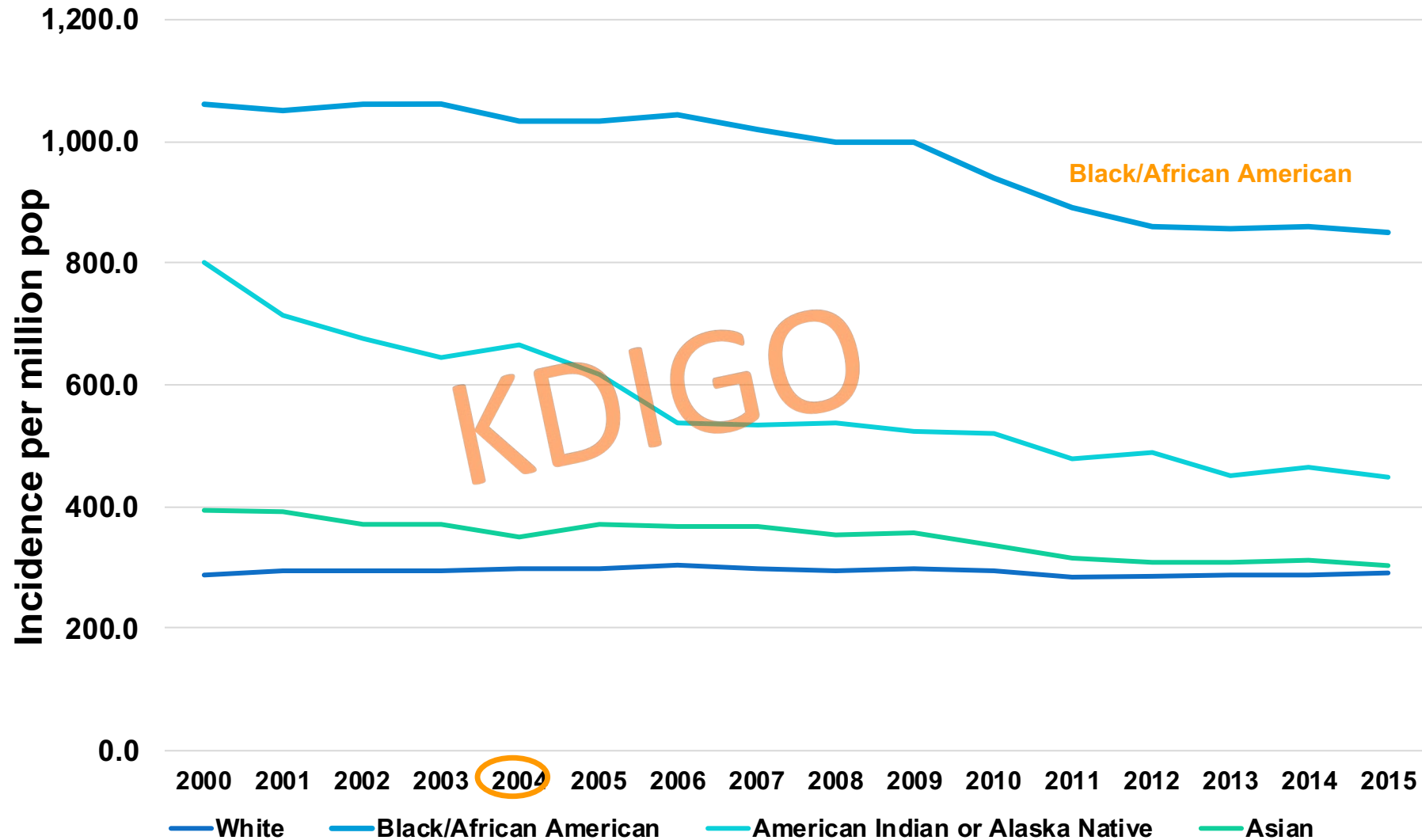


- Goal of Dialysis Treatment-
Rehabilitate the Patient
- Home Dialysis
- Priority of Patient
Engagement
- Bridge to Kidney Transplant
- Prophecy

Prevalence of CKD 3-5



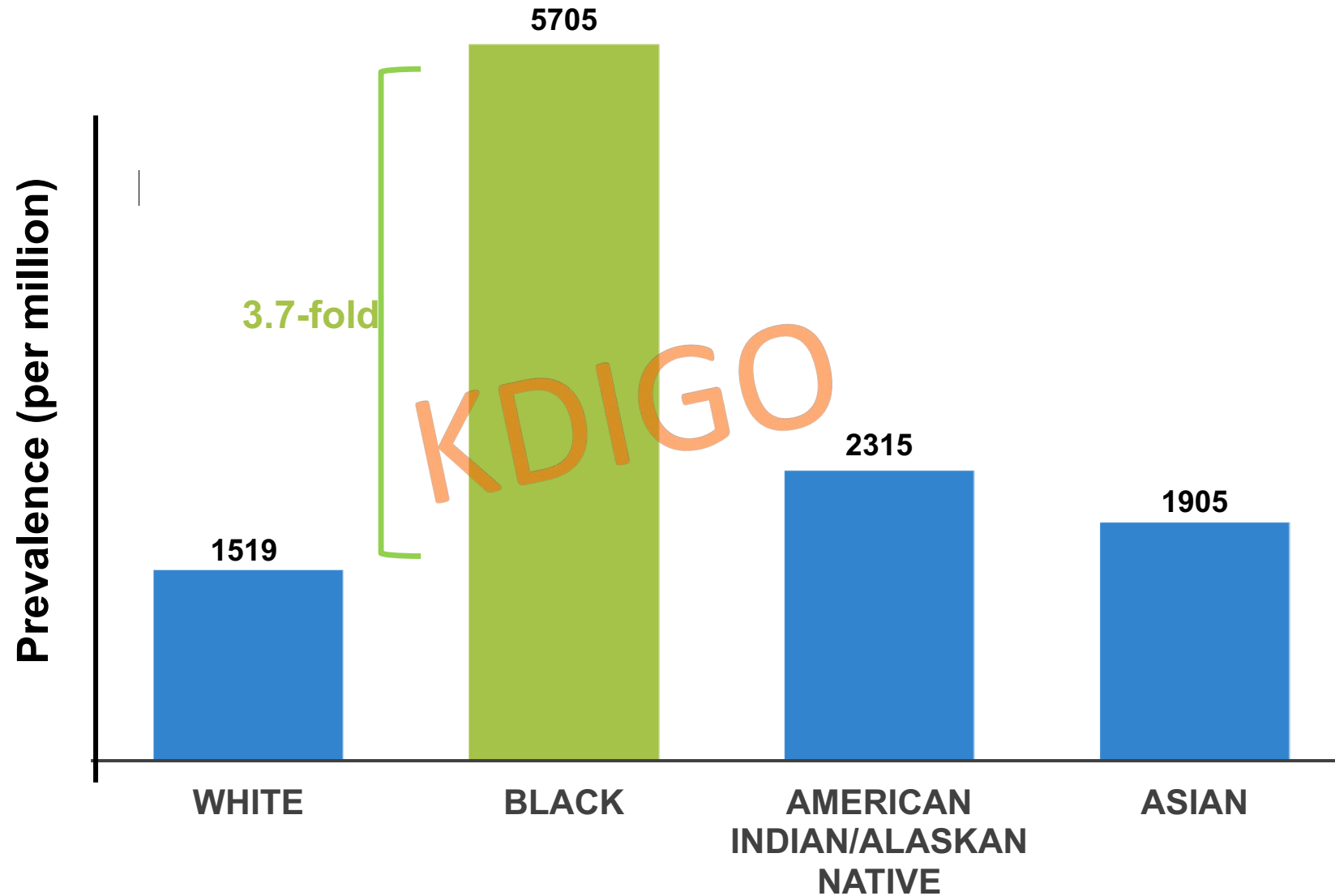
Trends in ESRD incidence in US, race



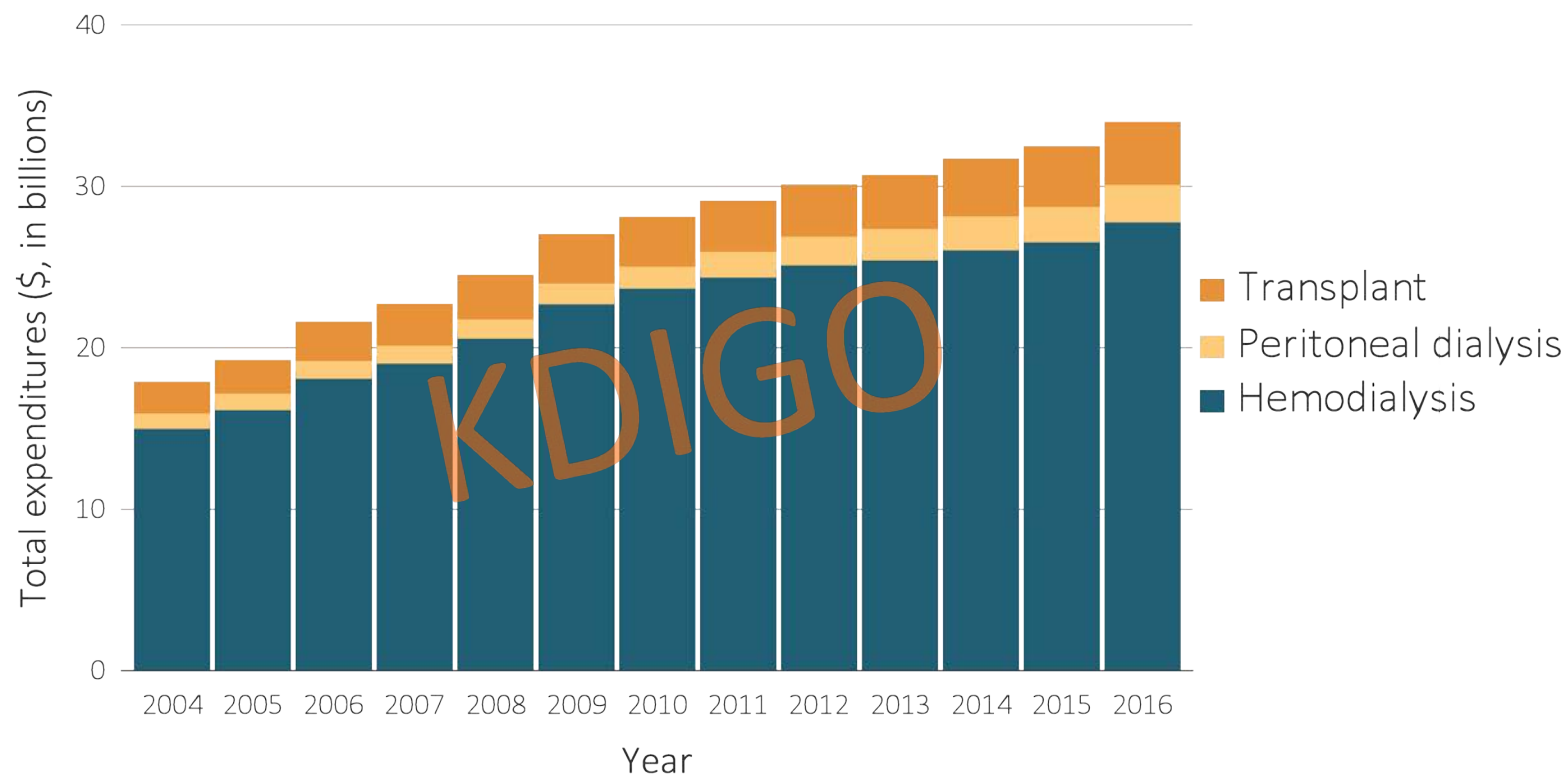
By age, sex, race, ethnicity and primary CKD cause

2017 USRDS

Prevalence of ESRD



vol 2 Figure 9.7 Total Medicare ESRD expenditures, by modality, 2004-2016



Data Source: USRDS ESRD Database. Total Medicare costs from claims data for period prevalent ESRD patients.

Abbreviation: ESRD, end-stage renal disease.

Trends in ACE/ARB and Angiotensin II Use with Impaired Kidney Function in US

ACE/ARB: Use Increased 1999-2014

Utilization Plateaued in 2003

<50% Utilization in CKD Patients

State of Nephrology Profession

- 40% of Nephrology Fellowships Unfilled (Appointment Year 2018)
- Poor Job Satisfaction and Burnout
- 5850 Oncology Clinical Trials vs <500 Kidney Disease Clinical Trials (2017)
- 29 Oncology approvals vs 2 Kidney Disease approvals (2015-2017)

Unprecedented Opportunity

**Kidney Health
Initiative**

**Kidney Precision
Medicine Project**

**KDIGO
ASN**

Kidney X

Executive Order

Surrogate Endpoints for Kidney Disease Clinical Trials

European Medicines Agency
Food and Drug Administration
National Kidney Foundation



Therapeutic Interventions on the Horizon

- ADPK
- Alport Syndrome
- Diabetic Kidney Disease
- FSGS
- IGAN
- SGLT2i

My Aspiration

- Patient-Centered
- Risk-Benefit Conversations
- Innovation
- Invest in Patient Engagement

KDIGO

THE
EMPEROR
OF ALL
MALADIES



VIDD HARTHA
KHERJEE