EARLY IDENTIFICATION & INTERVENTION IN CKD

Kevin Fowler
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
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
Barriers to Patient Engagement

- 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
Trends in ESRD incidence in US, race

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

2017 USRDS
Prevalence of ESRD

Prevalence (per million)

- WHITE: 1519
- BLACK: 5705 (3.7-fold)
- AMERICAN INDIAN/ALASKAN NATIVE: 2315
- ASIAN: 1905

USRDS 2017 Annual Data Report
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

Kidney X

Executive Order

ASN
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