

Why we need a patient-centered Global Nephrology Summit?



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Partnering to Summit

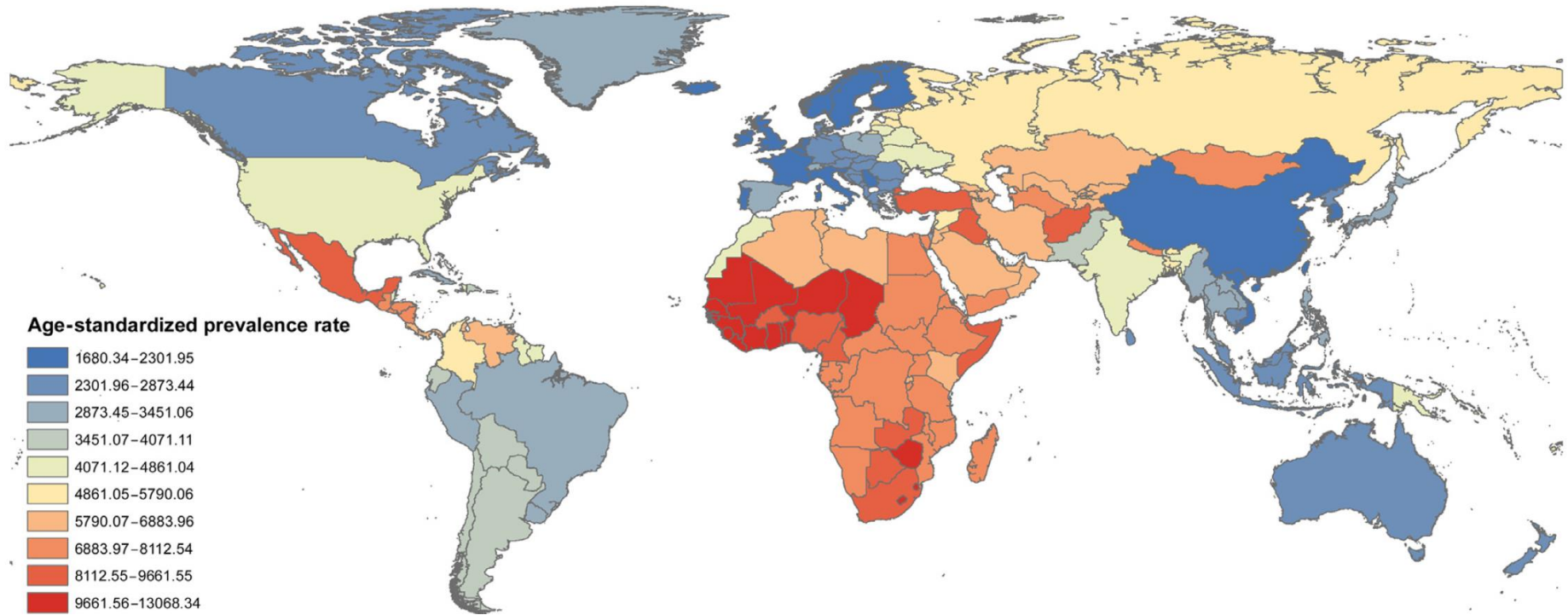
- The AAKP started in 1969
- Nationally recognized patient organization that reaches over one million people
- Committed to improving the quality of life for kidney patients through education, advocacy and patient engagement
- 1824-GW School of Medicine was founded
- First in the Nation's capitol and 11th in the nation
- 1956- First hemodialysis performed at GW Hospital
- 1964- opened Washington's first non-military dialysis unit

Global CKD Epidemic



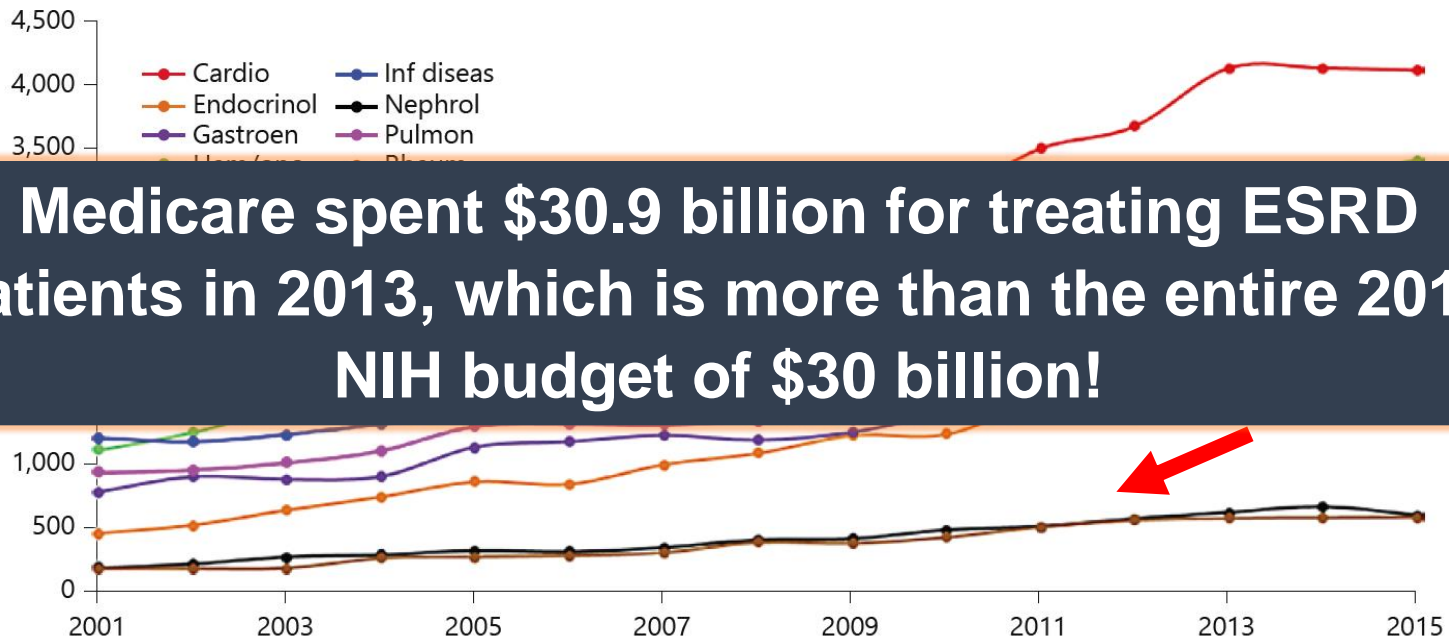
- 850 million people with CKD worldwide
- Cause at least 2.4 million deaths per year
- It is the 6th fastest growing cause of death

Global Burden of chronic kidney disease epidemiology from 1990 to 2016



- ❑ The prevalence of CKD increased by 87%
- ❑ Death and disability due to CKD increased by 98%
- ❑ The burden of CKD larger in developing countries

Impact of Recent Clinical Trials on Nephrology Practice: Are We in a Stagnant Era?



Annual NIH expenditure for research by specialty*

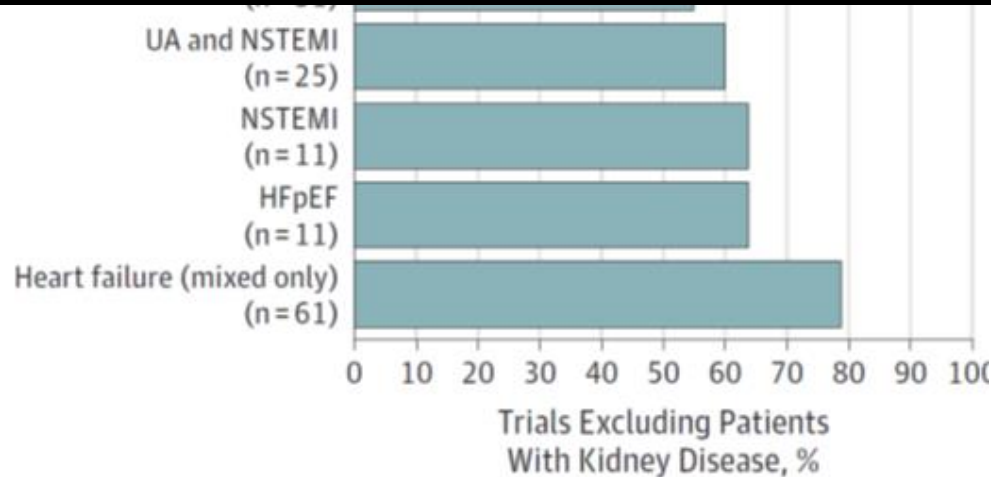
- 30 USD per CKD patient
- 500 USD per patient with cancer
- 2,500 USD per individual with HIV infection

Representation of Patients With Kidney Disease in Trials of Cardiovascular Interventions:

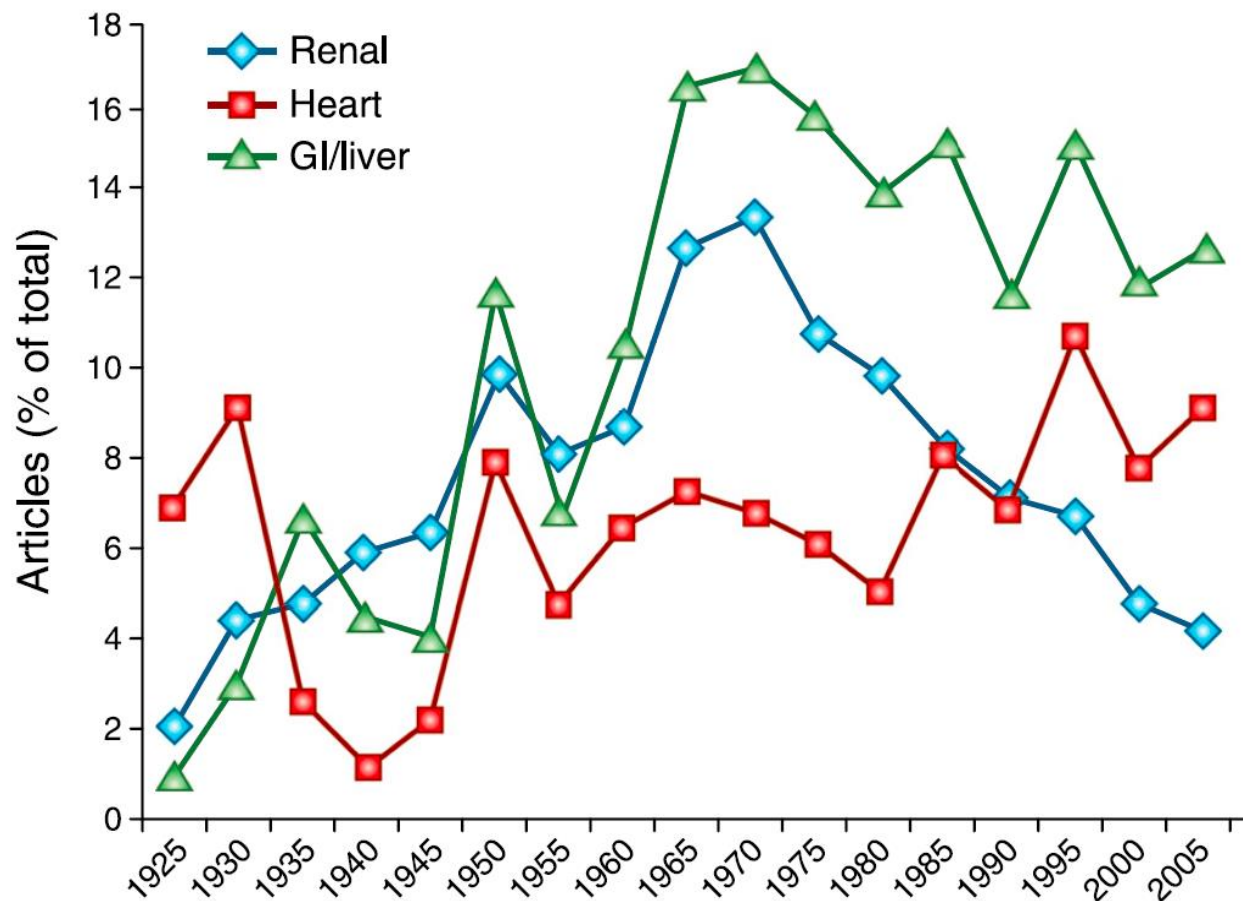
November 2014 to August 2015



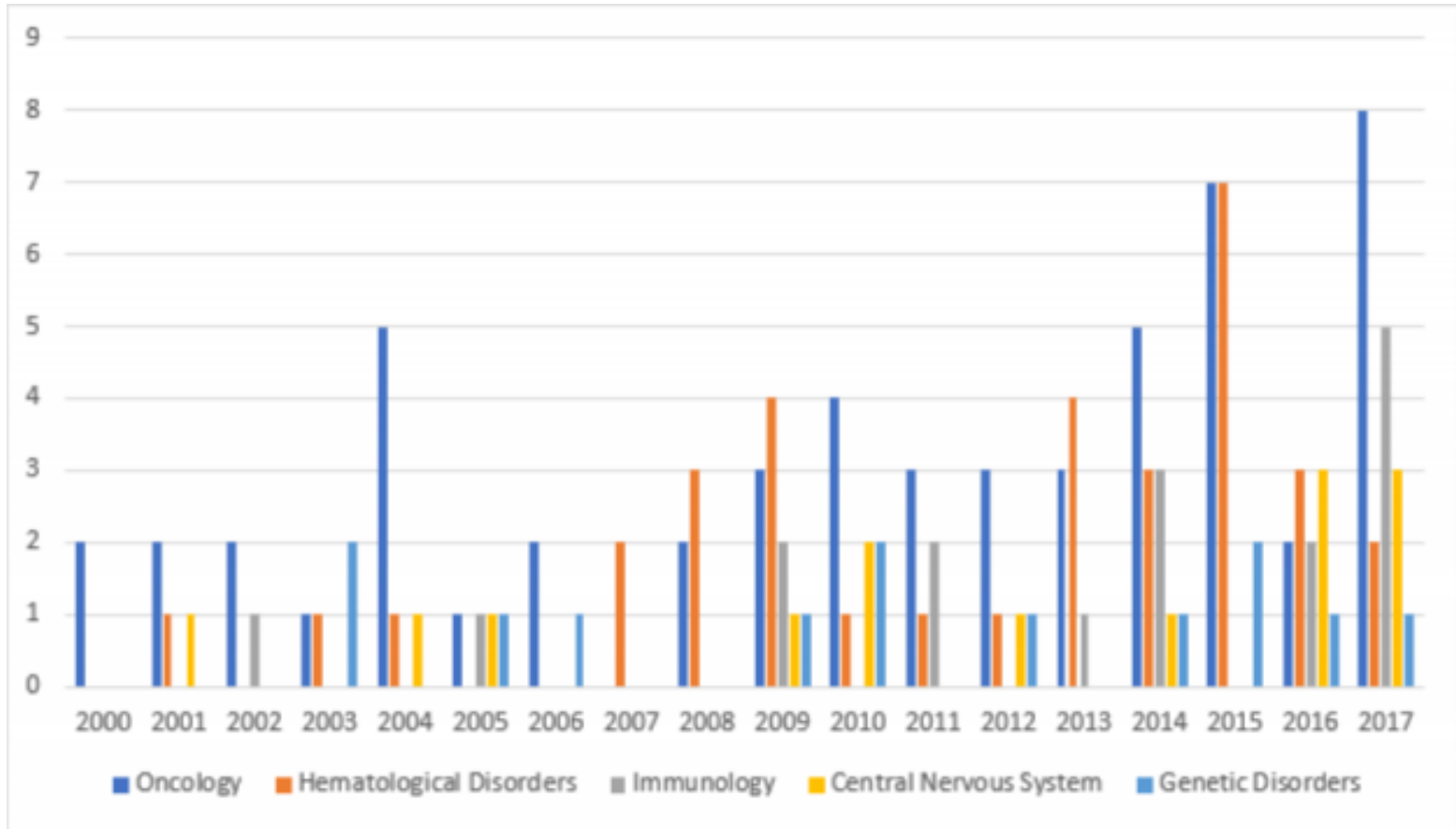
Yet, of the 371 CVD intervention trials conducted between 2014 and 2014, 212 (57%) excluded patients with kidney disease!



Basic Research in Nephrology: Are We in Decline?



Trends in FDA approval of Specialty Drugs 1990 through 2017



<http://rjhealth.com/2017/12/15/trends-fda-approval-specialty-drugs-1990-q3-2017/>

Ode to the kidney

Composition of the blood is determined not by what the mouth ingests but by what the kidneys keep; they are the master chemists of our internal environment

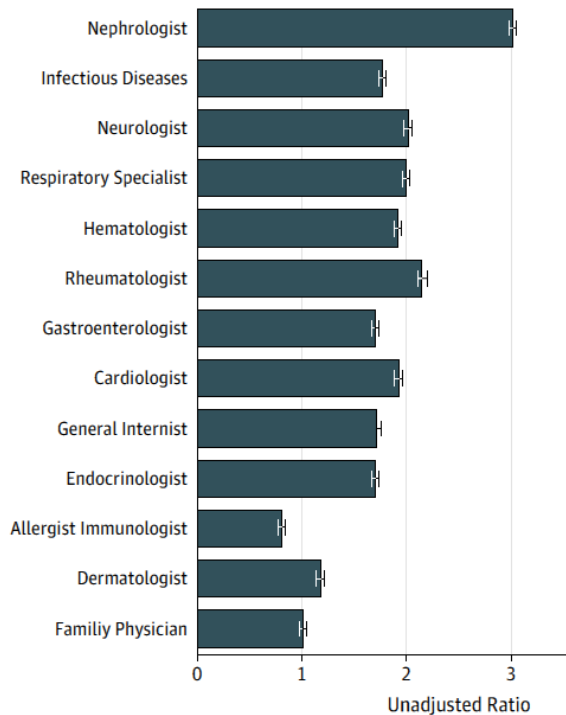
Bones can break, muscles can atrophy,, even the brain can go to sleep, without endangering our survival, but when the kidneys fail, neither bone, muscle, ... nor brain can carry on



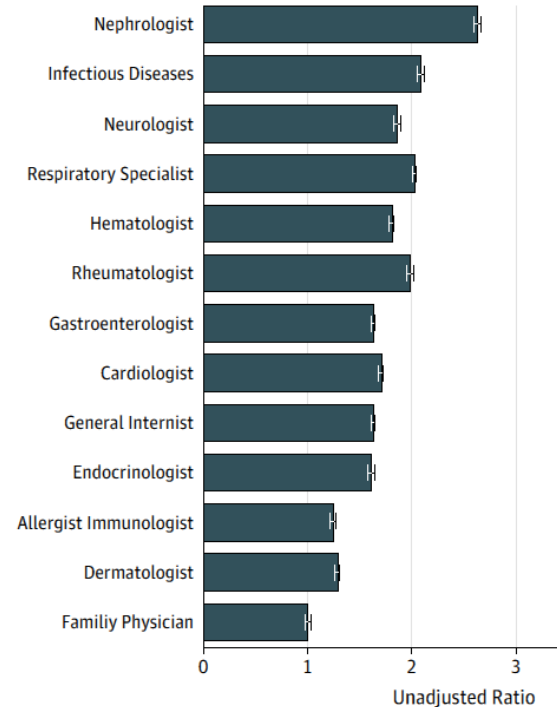
Homer W Smith, Lectures on the Kidney, 1943

Comparison of the Complexity of Patients Seen by Different Medical Subspecialists in a Universal Health Care System

A Comorbidities, No.



C Prescribed medications, No.



Patients seen by nephrologists have the highest number of comorbidities, highest number of prescribed medications and highest rate of death

The US Adult Nephrology Workforce 2016

Developments and Trends

Prepared for
The American Society of Nephrology

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Richard Bright's Reports of Medical Cases (1827): A sesquicentennial note

HOMER WILLIAM SMITH

1895—1962

The Kidney: Structure and Function in Health and Disease.

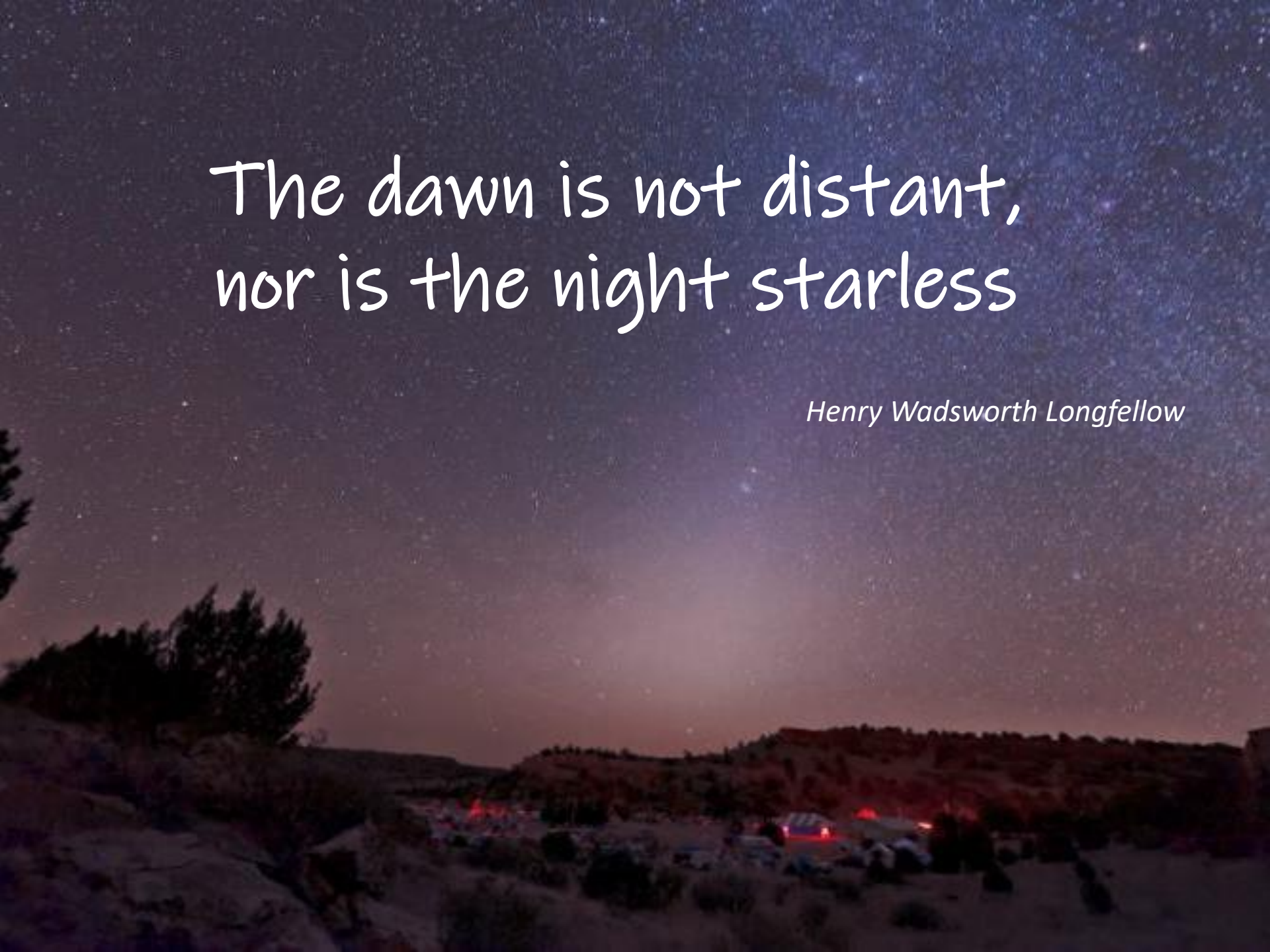
Belding Scribner -- perfected kidney

dialysis Millions of people are alive today because of his seminal work on the artificial kidney

John P. Merrill

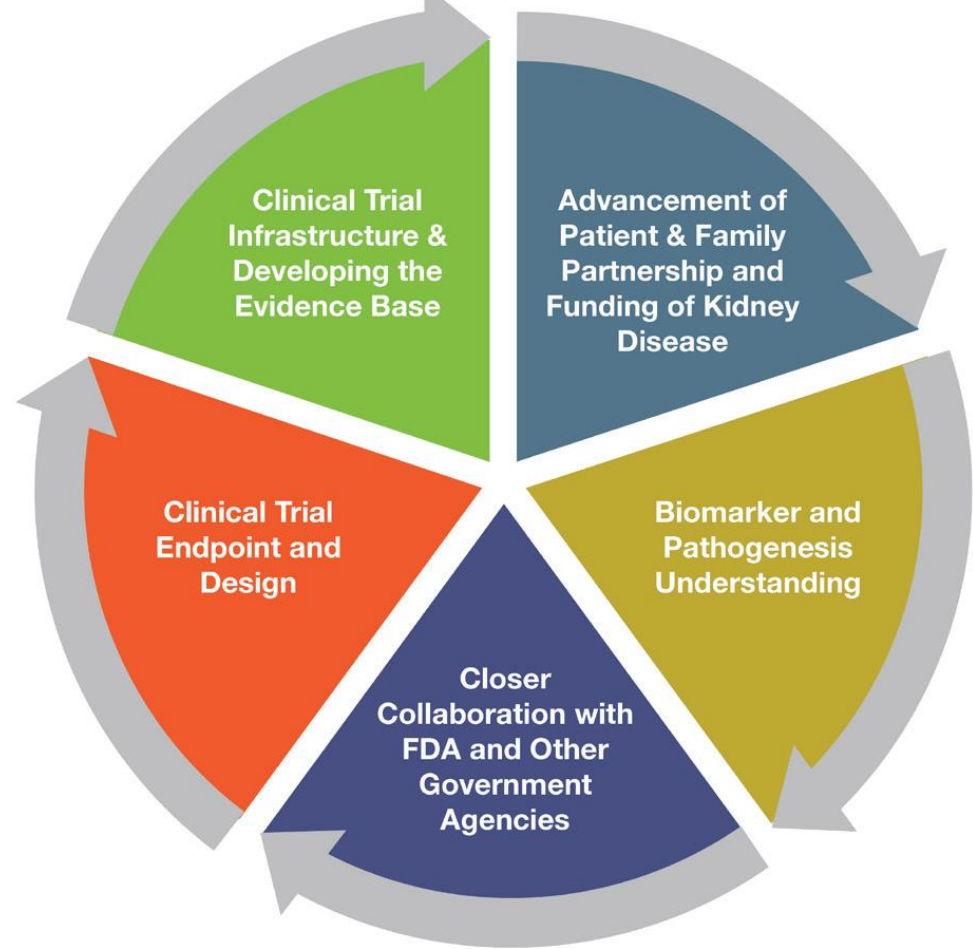
The Father of Nephrology as a Specialty

Today, hundreds of thousands of patients with ESRD in every corner of the globe are enjoying fulfilling lives as a result of Merrill's pioneering efforts in developing extracorporeal dialysis, transplantation, and transplant immunology.



The dawn is not distant,
nor is the night starless

Henry Wadsworth Longfellow



KHI was founded in 2012 toto foster development of therapies by creating a collaborative environment in which FDA and the nephrology community could interact

**Congressional Kidney Caucus
Hosts Capitol Hill Briefing
Highlighting Need for Increased
Investment and Resource
Coordination to Address Nation's
Kidney Disease Epidemic**

September 28, 2018

Complementary Initiatives from the NIDDK to Advance Kidney Health



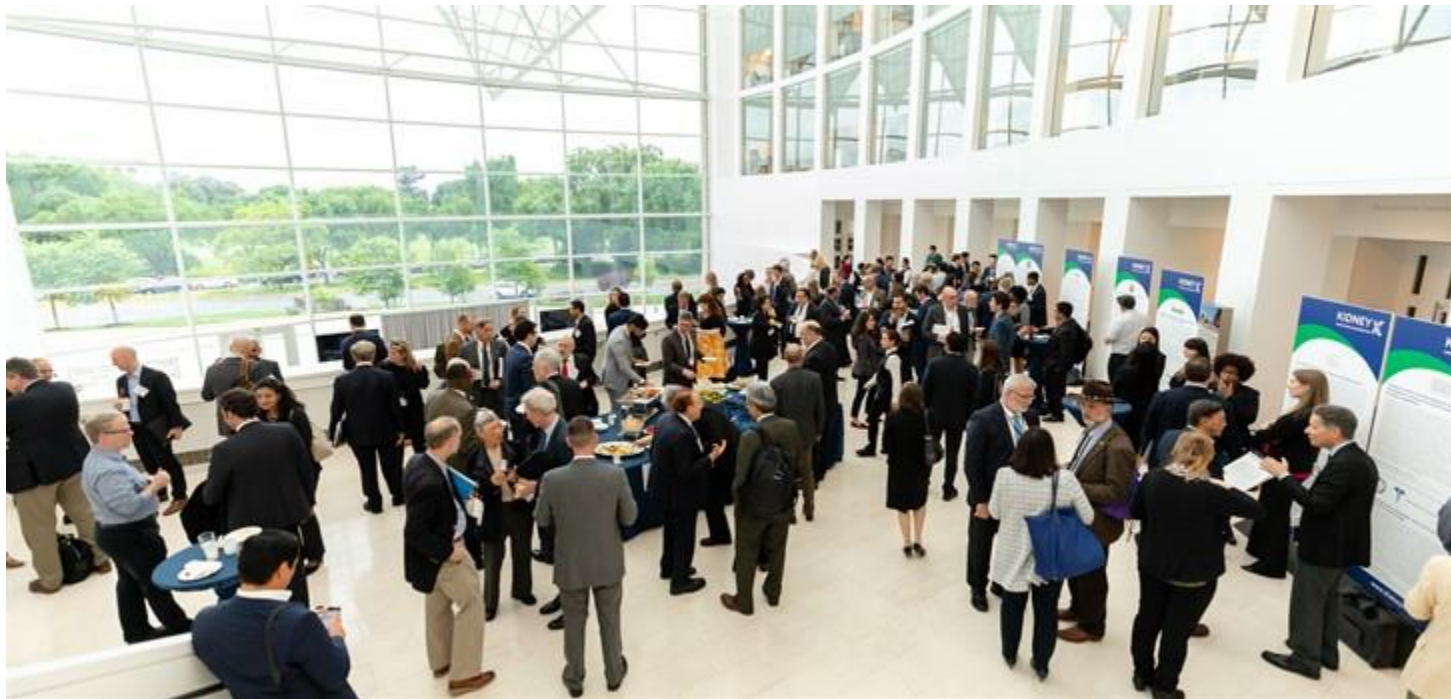
To create a kidney tissue atlas, define disease subgroups, and identify critical cells, pathways, and targets for novel therapies

The *APOL1* Long-Term Kidney Transplantation Outcomes Network—APOLLO

The APOLLO study is being done in an attempt to improve outcomes after kidney transplantation and to improve the safety of living kidney donation based upon variation in the apolipoprotein L1 gene (APOL1)



A partnership between the US Department of Health and Human Services and the American Society of Nephrology to accelerate innovation in the prevention, diagnosis, and treatment of kidney diseases.



What we Aim to Accomplish?

1. To put policy insights and perspectives from diverse sectors of kidney health in the context of cutting edge science and innovative practice solutions
2. To identify challenges, discuss solutions, and define the research needed to inform and evaluate policies in order to improve kidney health
3. To discuss inequalities in care delivery, explore opportunities to improve kidney health through global strategies, alliances and policies

To Sum ...

- There is a large global burden of CKD with poor outcome
- Decreased resources allotted to kidney research has led to paucity of innovation in the nephrology
- Lower compensation and higher work load has resulted in reduced nephrology work force
- Partnership among patients (organization), policy makers, providers, inventors and investors is crucial for innovative discoveries and delivering them to our patients

**“When he took time to help the man up
the mountain, lo, he scaled it himself.”**

– Tibetan Proverb

Thank you

