Patients and Their Government:

Shared Expectations and Responsibilities

Determine High Impact Engagement
Snapshot: Kidney Disease

- 26 million est. Americans with kidney disease
  - 570,000 + with ESRD
  - 450,000 + receive dialysis 3X per week
  - 186,000 + live with a kidney transplant
  - 100,000 + await transplantation

- $87 billion/yr Medicare for kidney disease patients
  - $58 billion/yr Medicare cost for CKD (stages 1-4)
  - $29 billion/yr ESRD program

- $86,592/yr cost of dialysis

- $24,438/yr cost of transplant (yr/1 = $125,967)
Key Challenges

• In CKD/ESRD, disease knowledge and management has advanced – but treatment is largely unchanged

• Cost of disability and unemployment for kidney patients and taxpayers mounting

• Questions about capability of government to keep pace with innovation and patient demand
Forces Driving Healthcare Innovation

• Applied medical and pharmaceutical research
• New information technology and applications
• Application of “big data” and data analytics
• Remote medical monitoring devices
  – (emerging players such as Google)
• Changes in law and regulation (ACA)
• Promise of a more responsive government
• Social media impact of patients and caregivers
Healthcare Stakeholders

- President/U.S. Congress
- Federal Regulatory & Oversight Agencies – HHS, CMS, CMMI, FDA, NIH, IOM, GAO
- State Government
- Professional Medical and Research Organizations
- Lobbies (LDO’s, SDO’s, Pharmaceuticals, Hospitals)
- Inventors, Investors & Manufacturers
- Think tanks/Non-Profits (501 c3/501 c4)
- Traditional Media/New Media

YOU – PATIENT & CAREGIVERS
Social Media Power

- **Facebook 58%** (71% of adult internet users, average friend group is 155)
- **Linked In 23%** (28% of adult internet users)
- **Pinterest 22%** (28% of adult internet users)
  
  NOTE – 42% of online women use Pinterest compared with 13% of online men.
- **Instagram 21%** (26% of adult internet users)
  
  NOTE – 53% of 18-29 now use Instagram, compared with 37% in 2013.
- **Twitter 19%** (23% of adult internet users)
Patient Demands Drive Government Response

• Patient Engagement & Patient Centered Care
• Patient Centered Care Outcomes Research
• PCORI – Patient Centered Outcomes Research Institute (per ACA – a “think tank”)
• Patient Reported Outcomes (PRO’s)/Alternative Clinical Trial Endpoints
• Patient Preferences/Patient Preference Analysis
• Receptiveness to Patient Advocacy
• “Quality Of Life” – as defined by patients
Expectation: Trust & Respect

Responsibilities

Government

• remember government serves the people
• understand patients are citizens and voters
• patients are defined by entire life – not disease

Patients:

• understand civil service is honorable
• government alone is not the solution
Expectation: Confidentiality

Responsibilities:

Government:
- patient insights, unless mutually agreed to, are sensitive
- systems used to manage patient specific comments must be secure

Patients:
- speculative information shared through engagement is confidential
Expectation: Candor

Responsibilities

Government

• use plain language
• discuss medical risks and benefits directly
• avoid false expectations on impact of input

Patients:

• speak up - if something is unclear - state it
Expectation: Transparency

Responsibilities

Government

• answer the question upfront of “to what end” is patient preference data used
• use patient input to advance patient care choices – not to limit care options

Patients

• educate yourself on both process and outcomes
• ask questions and follow developments
Expectation: Advocacy

Responsibilities

Government:
• incorporate patient voice, especially from hard-to-reach and under-represented communities
• create more input opportunities within regulatory process

Patients:
• seek out and honor requests for involvement
• inform the Congress of positive agency efforts
Where We Go From Here

• Be open-minded and creative – contribute!

• Know your impact – your voice educates government, researchers, regulators, device manufacturers, the Congress and the media

• Share your activity on your social networks

• Keep learning and participating:
  – FDA – advisory councils, patient registries, clinical trials, forums, public hearings
  – KHI – Patient and Family Partnership Council, events
AAKP

- Largest, *independent* kidney patient organization in America
- Over 100,000 patient and caregiver members
- Majority of members are CKD and ESRD patients, significant number of transplant patients
- Increasing numbers of family and caregivers
- Expanding numbers of healthcare professionals including doctors, nurses, technicians, dieticians and social workers
AAKP Legacy – Highlight

• AAKP founders played central role in passage of 1972 legislation that amended the Social Security Act to cover dialysis treatment
• The 1972 legislation was signed into law by President Richard Nixon in 1973
• The legislation gave rise to the End Stage Renal Disease Program (ESRD)
• The ESRD Program is the only disease specific entitlement program in America
Strategic Principles

• Elevate patient voice in national policy debates and throughout drug and device development
• Protect the unique relationship between patients and their doctors.
• Educate patients and preserve their choices as informed consumers of healthcare
• Maintain AAKP independence in all national policy and operational decisions
• Operate on the policy of “no surprises” among trusted allies and government officials.
Select NGO Collaborations

- American Society of Nephrology
- Kidney Health Initiative (KHI – ASN/FDA)
- Renal Physicians Association
- National Kidney Foundation
- Alliance for a Stronger FDA
- National Renal Administrators Association
- American Nephrology Nurses Association
- Polycystic Kidney Disease Foundation
- Friends of HRSA
- Friends of NIDDK
- Forum of ESRD Networks
Advocacy Operations

• AAKP is *bipartisan* in our relationships and *non-partisan* in operations
• AAKP was unaffected in terms of influence following the 2014 changes in Congress
• We target *both* key committees as well as individual Senators and Congressional leaders impacted by kidney disease
• In addition to the Congress, AAKP maintains solid relations with GAO, CBO and OIG’s
Congressional Focus

**U.S. Senate (including leadership):**
- Appropriations Committee
- Health, Education, Labor Committee (HELP)
- Committee on Homeland Security & Governmental Affairs

**U.S. House (including leadership):**
- Appropriations Committee
- Energy and Commerce Committee
- Committee on Government Oversight & Reform

**Other:**
- Kidney Caucus; Congressional Black Caucus
Federal Agency Focus (Implementation)

- OMB
- HHS
- CMS (*ex*: 5 Star Dialysis Rating System)
- CMMI (*ex*: ESCO)
- FDA
- NIH
- HRSA (*ex*: Living Donation)
- NIDDK
Determining Allies

- Are They Principled Fighters?
- Experienced Practitioners in Multiple Arenas?
- Demonstrated Results – National or State?
- Shared Belief in Planning & Flexible Response?
- Long-Term Thinkers?
- Short-Term Emotion Based Actors?
- Trusted Inside Players?
Alliance Risks To Avoid

- Discredit to the AAKP Mission
- Confuse AAKP Messages/Legacy
- Turn Away Potential Long-Term Allies
- Discourage Elected/Policy-maker Interest
- Fulfill a Negative Narrative Already Underway