BMA Medicare Advantage Summit

July 23, 2019
Richard Knight, AAKP President
Mission

1. **Educate:** Patients and caregivers on CKD, ESRD, nutrition, kidney therapies including dialysis – PD and Hemodialysis (home and center) – and transplantation (including pre-emptive).

1. **Advocate:** For innovation and policy that improves treatment and extends life for kidney disease patients, align modalities with patient aspirations and always defend patient choice.

2. **Define:** “Patient Engagement” as a substantive tool to impact research, patient outcomes and national policy.
Key Distinctive

- We are a long-standing national education & advocacy organization with **creditability based on independence & fairness** – we are not “reactionary” and we do not “burn allies.”

- AAKP is grassroots with a **patient-lead** and patient majority BOD.

- We are known for **credible & knowledgeable leadership** when invited “to the policy table.”

- We are rarely “**missing from the policy table.**”
Patient Engagement
Capitol Hill Advocacy: 5 Year Trend

Hill Visits

<table>
<thead>
<tr>
<th>Year</th>
<th>Hill Visits</th>
</tr>
</thead>
<tbody>
<tr>
<td>2015</td>
<td>100</td>
</tr>
<tr>
<td>2016</td>
<td>150</td>
</tr>
<tr>
<td>2017</td>
<td>200</td>
</tr>
<tr>
<td>2018</td>
<td>250</td>
</tr>
<tr>
<td>2019</td>
<td>600</td>
</tr>
</tbody>
</table>
### Center for Patient Engagement & Advocacy

<table>
<thead>
<tr>
<th>Engagement</th>
<th>Advocacy</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Appointment of patients to Federal and State advisory opportunities (Technical Evaluation Panels, etc)</td>
<td>• Washington, D.C. “Capitol Hill Day” Visits</td>
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<tr>
<td>• Veterans Health Initiative (VHI)</td>
<td>• U.S. Public Service &amp; Congressional Leadership Awards Program</td>
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<tr>
<td>• National Ambassador Initiative</td>
<td>• Federal agency patient visits (CMS/FDA)</td>
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<tr>
<td>• AAKP webinars</td>
<td>• Congressional letters &amp; petition campaigns</td>
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<tr>
<td>• Flash surveys/questionnaires</td>
<td>• Public policy training workshops (web-based/in-person)</td>
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<tr>
<td>• AAKP Medal of Excellence Program</td>
<td>• Patient Advocacy Training Guides (online/mobile ready – in development)</td>
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### Center for Patient Research & Education

<table>
<thead>
<tr>
<th>Research</th>
<th>Education</th>
</tr>
</thead>
<tbody>
<tr>
<td>• PCORI (all 17 kidney projects, 10+ years)</td>
<td>• National Patient Meeting (largest in USA)</td>
</tr>
<tr>
<td>• AAKP Patient Database (continual data collection by disease stage) PLUS Demographic &amp; geo-targeting</td>
<td>• aakpRENApLIFE (national patient magazine)</td>
</tr>
<tr>
<td>• Clinical Trial Awareness Campaigns</td>
<td>• Print/Online Learning:</td>
</tr>
<tr>
<td>• Market Research (full product lifecycle)</td>
<td>• Healthlines (targeted by issue/audience)</td>
</tr>
<tr>
<td>• Consulting for Patient Advisory Panels &amp; Council creation</td>
<td>• AAKP “Understanding Kidney Disease” AAKP “Kidney Beginnings”</td>
</tr>
<tr>
<td></td>
<td>• Nutrition/AAKP Delicious! Recipe Cards</td>
</tr>
</tbody>
</table>
TOP PATIENT INFLUENCERS IN USA

Since 2017 Creation

- 120+ Ambassadors in 47 States, plus D.C.
- Highly informed kidney patients
- Strong social media networks
- Frequent visits to Capitol Hill
- Serve on Federal advisory boards
- High clinical trial experience

2020

- Global Expansion
- 400 – Every Congressional District
Center for Patient Research & Education

During the past 16 months, AAKP has been contacted by more than 63 companies, investment firms and major investors on questions related to trial and research related issues to provide patient preference and insights for:

- Study design/protocols
- Participant consent forms
- Study/participant materials (i.e. patient facing items such as marketing, use of appropriate language, images and graphics)
- Trial recruitment efforts
- Patient burden assessments
- Targeted patient surveys
- In-person on online video focus groups
- Cognitive interviews

In the same period, AAKP has had over 135 other contacts with government, private sector and research institutions on patient insights related to new drug/device/diagnostic regulation, reimbursement and patient consumer choice.
AAKP’s 50th Anniversary

2019 is a milestone year for AAKP as the organization marks 50 years of successful patient engagement and advocacy. AAKP is the oldest and largest, fully independent kidney patient organization in the U.S.A. Founded in 1969 by six dialysis patients, with doctor encouragement, our Founders helped create the End Stage Renal Disease (ESRD) Program, saving more than one million lives since 1973.

Join us in celebrating all year long!

https://aakp.org/50thanniversary/
AAKP Educational Materials  aakpRENA LIFE

- Reaches 22,000+ total subscribers, is sent to over 6,000 dialysis clinics and receives over 400,000 views on our online platforms!

E-newsletters
- aakpRENA FLASH: 8,000 subscribers
- Kidney Transplant Today: 4,500 subscribers
- Kidney Beginnings: 8,200 subscribers
- At Home with AAKP: 3,200 subscribers
- AAKP Kidney Pediatric Pals: 91 subscribers
HealthLine webinars

2019 Topics:
• Taking Care of Yourself While Taking Care of Others – Coping Strategies for Kidney Patient Caregivers January
• For the Love of Plants – What to Know When Considering Plant-based Nutrition February
• 3-part Series on Pediatric Patients:
  • What to Expect When Your Child Starts Dialysis March
  • Tips for Care Partners on How to Support Pediatric Kidney Transplant Patient April
  • Growing Up as a Kidney Patient – Transitioning from Pediatric to Adult Care April
• Understanding Secondary Hyperparathyroidism – What is it? How can it be managed? May
• Yes, You CAN Travel While on Dialysis! June 27, 1:00 pm ET
• Getting (and Staying!) Active with Kidney Disease July 23, 1:00 pm ET
• Potassium August, date and time TBD

https://aakp.org/aakp-healthline/
44th Annual National Patient Meeting

Join us September 6 - 8, 2019 in Washington, D.C.

Patient scholarships available! August 16th deadline

https://aakp.org/national-patient-meeting/

Hyatt Regency Washington on Capitol Hill
SOCIAL MEDIA
One Click – Join Team AAKP

@kidneypatient

@kidneypatients

www.linkedin.com/company/american-association-of-kidney-patients

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