National Strategy Overview

Center for Patient Engagement & Advocacy

Center for Patient Research & Education
The American Association of Kidney Patients (AAKP) is the oldest and largest, fully independent patient-led, kidney patient education and advocacy organization in America. For more than 50 years, AAKP has been the leader in the fields of patient engagement, patient-centered education, and public advocacy efforts. AAKP is proud of our legacy, and we consider ourselves among the original pioneers of increased access to high quality care for kidney patients. One of our earliest advocacy achievements with White House officials and the United States Congress was the 1973 End Stage Renal Disease (ESRD) Program, administered by the Centers for Medicare and Medicaid Services (CMS). This is the only disease-specific entitlement program in the United States and has saved well over 1 million American lives through dialysis kidney transplantation since it was enacted by a bipartisan majority and signed by President Richard Nixon.

AAKP is an IRS registered Sec. 501(C) (3) non-profit, non-partisan organization, governed by a patient-majority National Board of Directors. AAKP was founded in 1969 by six kidney patients who were brought together by their disease, their shared prospect of a premature death and an intense desire to undergo and expand the availability of the still experimental and highly risky process of dialysis. These pioneers of patient engagement set out to inform fellow patients and the public about the devastating impact of kidney disease for both patients and the families that depended upon them.

These AAKP Founders – and their compassionate care teams - knew their actions and would impact not only their own lives, but the lives of patients who they might never meet in the years and decades ahead. Just as importantly, they knew that selfless activism alone - absent a National Strategy and the combined strength of powerful allies and sophisticated advocacy techniques – would not result in the national changes in treatment access and quality they sought for all kidney patients.

They developed and refined their strategy with industry partners and innovation leaders. As they moved forward together, they targeted specific Federal laws and regulations that posed either barriers or potential opportunities to best address the needs of kidney patients. These early AAKP patient advocates demonstrated courage and leadership as they publicly told their personal stories, sought out empathetic allies in academia, among medical professionals, visionaries in the pharmaceutical industry, and early leaders in the provider community and among elected and appointed leaders throughout government.

Their legacy of engagement in the national policy process, substantive impact on American policy and innovation and the preservation of innocent life informs every decision made by AAKP to this day.

**AAKP LEADERSHIP – NATIONAL RELEVANCE AND CAPACITY TO EXECUTE**

Today, AAKP works diligently to represent the more than 700,000 patients receiving dialysis care, those with kidney transplants, the nearly 40 million American adults suffering from chronic kidney disease (CKD), and individuals diagnosed with rare diseases / genetic disorders that cause renal complications and/or renal failure.

Kidney patients, as healthcare consumers and as a population that endures significant medical burdens, have gained support from a growing national and global alliance of research professionals, kidney medicine experts, elected and career government officials, and private industry executives.
and investors who share their desire to bring new prevention and treatment options to the market. To achieve this commonly held goal, patient advocates have become more sophisticated in their tactics, and innovation and policy leaders have placed a higher priority on incorporating patient insight data, patient preferences, and real-world evidence to help accelerate new product development and to better inform regulatory and payment decisions.

The AAKP has been at the center of this pivot in kidney medicine and innovation. The organization defines high quality kidney care as treatments that reduce patient burdens while allowing patients to pursue their aspirations, including part-time and full-time work, because AAKP sees kidney disease as both a healthcare issue and workforce issue. To that end, AAKP has expanded its capacities to increase patient impact on research and product development – for kidney disease and related health conditions kidney patients often face – by organizing and training patients and their care partners to engage effectively with leaders in science and innovation.

AAKP founded its Center for Patient Research and Education and Center for Patient Engagement and Advocacy in 2016 to serve as a rapid fulfillment hub for requests from kidney patient experts originating from government, academia, medical device manufacturers, and the pharmaceutical industry. The Centers also support AAKP’s National Strategy to expand patient care choice through wider access to safe, new diagnostics, devices, and drugs – without interference and artificial barriers erected by insurers and other payers. Since its launch, AAKP has also stood-up a sophisticated national Ambassador initiative, to ensure that the independent voices and social networks of kidney patients and their families are heard and leveraged. Since inception, the Ambassador initiative has expanded to increase representation of Veteran and Military Family Ambassadors, as well as globally to include International Ambassadors. Further, AAKP has dramatically expanded its membership and patient recruitment databases, communications platforms, and social media targeting and analytics tools.

The AAKP now services dozens of requests every year for clinical trial awareness and recruitment campaigns, patient advisory boards, technical evaluation panels, focus groups, patient surveys, clinical research, and public policy research. AAKP leaders and professional staff provide expert advice to organizations and companies on how to work meaningfully with patients as co-investigators and partners and offer online training for patients on how to be equally effective collaborators. Dozens of AAKP leaders nationwide have received U.S. presidential recognition via Presidential Volunteer Service Awards, from both President Joseph Biden and President Donald Trump, for their volunteer efforts in support of kidney disease education and medical innovation.

**AAKP’s mission is to improve the quality of life for kidney patients through education, advocacy, patient engagement and the fostering of patient communities.** AAKP fights for early detection; increased kidney transplantation and pre-emptive transplantation; full patient choice of either in-center or home dialysis; protection of the patient/physician relationship; promotion of research and innovation including artificial and wearable kidneys and xenotransplantation; and the elimination of barriers for patient access to available treatment options. At AAKP we....

1. **Educate:** patients and family members/care partners on important issues so individuals can better understand their condition and make informed decisions on their care options which align with their life goals and aspirations. AAKP is a recognized leader for patient-centered education – continually developing high quality, professionally written, edited and reviewed material.
2. **Advocate:** for policies that improve treatment and extend life for kidney disease patients – always defending patient consumer care choice. AAKP has been the independent patient voice – advocating for improved access to high-quality healthcare through regulatory and legislative reform at the Federal level. The Association’s work has improved long-term outcomes in both quality of health and quality of life, supporting the ability for patients and family members affected by kidney diseases to lead a more productive and meaningful life.

3. **Define:** “patient engagement” as a substantive tool to impact policy and health outcomes.

4. **Community:** AAKP is leading the effort to bring kidney patients together, both nationally and through AAKP Global™, to promote community, advance innovation, and to impact policies. We do this by maintaining and expanding our unique relationships among by elevating patient insights among an international network of researchers, clinical trial experts, innovators, companies, and government leaders.

As a national organization that reaches more than one million kidney patients and their friends and family members annually, AAKP is uniquely positioned as one, if not the most, impactful patient organization in the kidney community due to its patient-centered, patient-focused structure. As an organization that is run by patients, for patients, AAKP is able to keep the patient voice and interests in the forefront, making the Association highly regarded by the kidney community at large – including healthcare professionals; patients and family members; industry (pharma/providers); government agencies (such as HHS, CMS, CMMI, FDA, NIH, CDC, VA, DoD, etc.); and policy makers at the Executive and Legislative Branches.

The current National Board represents a purposely selected range of skills and expertise honed at the national level and selected from the fields necessary to implement the AAKP National Strategy. These fields include all medical and surgical specialties within the kidney disease field, public policy research and legislative advocacy, accounting, traditional and social media, academic program leadership, social work and disability program management, small business development, marketing, legal, patient safety, non-profit management, and corporate leadership.

Our national leadership serves in many very prominent capacities with the Federal government, including policy and evaluation roles within the Kidney Precision Medicine Project (KPMP) at National Institute of Health/National Institute of Diabetes and Digestive and Kidney Diseases; KidneyX, a partnership between American Society of Nephrology and U.S. Department of Health and Human Services; the Kidney Health Initiative (KHI) a partnership American Society of Nephrology and Food and Drug Administration; along with multiple other agencies including Centers for Medicare and Medicaid Services, Center for Medicare and Medicaid Innovation, Centers for Disease Control and Prevention, Veterans Administration, and Department of Defense.

AAKP bylaws state that more than 60 percent of Board Members must be patients and the president of the organization must be a patient. A complete Board Member list can be viewed at https://aakp.org/about/board-of-directors/ and a complete Medical Advisory Board list can be viewed at https://aakp.org/about/medical-advisory-board/.
AAKP – NATIONAL STRATEGY SUPPORTS OUR COMMITMENT TO PATIENT PROGRAMS AND INITIATIVES

AAKP’s relevance throughout the renal community is firmly established among patients and their family members as we continue to provide the necessary educational tools to understand their condition and appropriately manage their disease.

AAKP’s professional staff work closely with the AAKP Medical Advisory Board, AAKP program committees and patients to develop high-quality; patient-geared programs and materials that help educate and encourage discussion among patients and their healthcare team while empowering patients to become better managers of their own health outcomes and informed patient consumers. These programs are generously funded through individual donations and grants by industry, providers and pharmaceutical partners who share our commitment to quality education, patient care and consumer choice.

AAKP believes a unified approach is the best method to achieving a fulfilling life while managing kidney disease/failure. Each of our educational programs is subjected to critical review by our medical teams for accuracy and by our patient teams for relevance and ease of understanding and practical use. Every program is designed with the purposes of:

- **Preventing** and addressing renal complications.
- **Understanding** a full range of self-care and clinical treatment options for selecting appropriate therapies.
- **Identifying** barriers to optimal health and wellness.
- **Reinforcing** practical strategies to motivate change and achieve an overall improvement in health outcomes.

The AAKP engages in a number of multi-supported programs and activities that educate, advocate for and empower patients to understand their condition, take control of their illness, and make informed choices on the best course of treatment for them. AAKP firmly believes that an informed patient is a healthy patient.

The Association takes pride in its current and future programs, as all activities must:

- Further its mission.
- Meet the strict definition and guidelines of AAKP’s overriding initiatives (see Centers chart below).
- And most importantly, begin and end with patients and improved outcomes.

**AAKP Center for Patient Engagement and Advocacy.** The AAKP Center for Patient Engagement and Advocacy was created in 2014 to leverage AAKP’s increased profile and influence in the national public policy process and to expedite implementation of our National Strategy to vastly expand patient involvement in the decisions that impact their health outcomes. The Center for Patient Engagement and Advocacy brings, under one focused area, all AAKP efforts to build patient and family/caregiver membership in AAKP as well as their participation in existing and emerging AAKP patient health engagement and advocacy programs.

Additionally, as part of the AAKP National Strategy, the Center for Patient Engagement and Advocacy works to engage, train, certify and deploy kidney patients in ways that are the most effective at elevating the patient voice within Federal policy-making circles. This includes critical times when national legislation, health program implementation, regulations or potential delays in the
pharmaceutical approval process pose a concern to patient access to quality care or their future healthcare outcomes. AAKP is engaging and encouraging kidney patients and caregivers to participate in substantive opportunities for effective patient engagement and advocacy. At the heart of this Center is the AAKP Ambassador Initiative, launched in 2017, the program has grown to more than 170 + Ambassadors in nearly all 50 states plus D.C. In 2019, AAKP launched the AAKP Global™, an international arm of this initiative and now has Global Ambassadors in countries such as Ireland, Canada, Argentina, United Arab Emirates, Iran, Australia, and more. Ambassadors are AAKP’s most engaged volunteers who utilize their personal experiences and professional skills to contribute to both the AAKP mission and the larger kidney community based on their desire to serve a cause larger than themselves. These individuals also allow AAKP to expand our reach and resources to make a positive impact at the state and local level and globally.

Since 2018, AAKP has conducted the largest virtual kidney voter registration drive in America, the “I am a Kidney Voter” campaign, which has registered patients in every state. #IAmAKidneyVoter, #KidneyVoter. In 2022, AAKP stood up its Patient Voice Patient Choice™ initiative which mobilizes those impacted by kidney diseases by engaging them in ways that are most effective in elevating their voice in the policy and payment decisions that impact the access to new diagnostics, drugs, and devices that can improve and save their lives. The Patient Voice, Patient Choice™ initiative provides an interactive platform patients and care partners can use to quickly identify current issues impacting care choice and treatment.

In the past decade, AAKP patients have helped gain lifetime transplant drug coverage for kidney transplant recipients (2020); new patient-centered policies via the White House Executive Order on Advancing American Kidney Health (2019); new job protections for living organ donors from the U.S. Department of Labor (2018); and Congressional legislation allowing HIV-positive organ transplants for HIV-positive patients (2013).

**AAKP Center for Patient Research and Education.** AAKP firmly believes, as research has also shown, that patient and family member/caregiver education is an integral part of treatment and enhancing quality of life. Not educating a patient and their care partner about their condition and treatment options leaves the patient at risk for complications as well as the possibility of not selecting a course of treatment best suited for them. Education is a simple and effective way to improve overall health and achieve better outcomes.

In the same vein, AAKP is uniquely positioned to ensure the patient has a central role in research and other activities that are designed to determine optimal approaches and strategies for providing healthcare services, assistance programs, access to new products and services, etc. AAKP constituents represent all ages, modalities, ethnicities, disease states, and a variety of demographic indicators. AAKP’s research capabilities have grown rapidly, and the Association has created a sophisticated database and expansive social media channels which allow AAKP to better connect and learn from its constituents. In turn, AAKP provides education to patients and caregivers on what it means to be involved in research initiatives as well as opportunities to get involved. From online surveys, interviews, focus groups, and clinical trial awareness campaigns – AAKP is focused on inserting important patient insight and preferences into research to help inform innovation, advance care, and make a meaningful impact to improve lives – this means AAKP members are helping shape the future policies and discoveries that characterize kidney care!

AAKP is known within the renal community as a leader in quality education; taking time to produce programs and materials that are current, relevant and address the most pressing issues patients and their families face. AAKP is deliberate in its development of educational programs, working closely
with its Medical Advisory Board, health educators and fellow patients to create unbiased, reliable resources that are easily understood and beneficial to patients. AAKP routinely uses matrices to measure program outcomes to assess effectiveness and success as well as opportunities for enhancement. AAKP offers its programs in a variety of mediums to ensure we reach as many patients as possible (print, online/web-based, smart devices, live/in-person).

### CENTERS FOR PATIENT RESEARCH & EDUCATION AND ENGAGEMENT & ADVOCACY MODEL

The charts outlined below demonstrates how both AAKP’s Center for Patient Research & Education and Center for Patient Engagement & Advocacy are strategically aligned and complement each other for maximum effectiveness.

#### Center for Patient Engagement & Advocacy

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<thead>
<tr>
<th>Engagement</th>
<th>Advocacy</th>
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<tbody>
<tr>
<td>• Ambassador Initiative (National/International/Veterans/Military Families)</td>
<td>• Public Policy Summit (virtual/in-person)</td>
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<td>• Ambassador Toolkit/Handbook</td>
<td>• Public Policy Roundtables (virtual/in-person)</td>
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<tr>
<td>• Ambassador Certification Program - in development</td>
<td>• AAKP National/State Patient Advocacy Day/ Capitol Hill Day Visits (virtual/in-person)</td>
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<tr>
<td>• AAKP Veterans Health Initiative</td>
<td>• AAKP Action Center</td>
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<tr>
<td>• Engagement and Skills Training (web-based/in-person)</td>
<td>• KidneyVoter™ (register to vote campaign)</td>
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<tr>
<td>o Print Media</td>
<td>• Patient Voice Patient Choice™</td>
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<tr>
<td>o Social / Online Media</td>
<td>• Government Determinants of Health (GDoH)</td>
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<tr>
<td>o Radio &amp; Broadcast</td>
<td>• Advocacy and Skills Training (web-based/in-person)</td>
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<tr>
<td>o Patient Advisory Boards</td>
<td>o Policy Analysis</td>
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<tr>
<td>• Speakers Bureau: Patient/Living Donor/Caregiver (conferences, industry meetings, town hall meetings, interviews, media)</td>
<td>o Effective Advocacy</td>
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<tr>
<td>• Membership Services</td>
<td>o Voter Engagement Mobilization</td>
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<tr>
<td>• Flash surveys/questionnaires</td>
<td>o Comment letter writing</td>
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<tr>
<td>• The Decade of the Kidney™ (AAKP initiated and led)</td>
<td>• How to Become Your Own Public Policy Advocate (brochure)</td>
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<tr>
<td>• AAKP Global™</td>
<td>• Action Alerts</td>
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<tr>
<td>• Social Media</td>
<td>• Targeted Press Releases</td>
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<tr>
<td>o Facebook @kidneypatient</td>
<td>• Legacy Awards Program</td>
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<td>o LinkedIn American Association of Kidney Patients</td>
<td>• Patient Engagement &amp; Advocacy Awards Program</td>
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<td>o X/Twitter @kidneypatients</td>
<td>• Public Service &amp; Congressional Awards Program</td>
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<td>o YouTube @americanassociationofkidne3513e</td>
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<tr>
<td>• Peer Mentor Program</td>
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#### Center for Patient Research & Education

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<tr>
<th>Research</th>
<th>Education</th>
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<tr>
<td>• Global Summit on Kidney Innovation (virtual/in-person)</td>
<td>• AAKP Website (<a href="http://www.aakp.org">www.aakp.org</a>)</td>
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<tr>
<td>• Research and Skills Training Sessions</td>
<td>• AAKP Shared Decision Making Guide (print/online)</td>
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<tr>
<td></td>
<td>• COVID-19 Education/Resource Center</td>
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- Research
  - Technical Writing
- Clinical Trial Awareness Campaigns
- Market Research Recruitment
- Geographic targeting of patients for specific engagement efforts
- Demographic targeting of patients for specific engagement efforts
- AAKP Constituent Database (continual data collection)
- Patient Advisory Panels/Councils
- Patient Roundtables
- Focus Groups (web-based/in-person)
- Direct patient interviews (one-on-one)
- Patient surveys (web-based/telephone)
- Fabry Disease Diagnostic Testing Project
- AAKP Intergalactic™

- National Patient Meeting
- Medal of Excellence Award Program
- Pocket Guide series (print/online programs)
- Nutrition Program/AAKP Delicious! (print/online/App programs)
- Kidney Beginnings series (print/online/interactive programs)
- Patient Plan series (print/online/interactive programs)
- aakpRENAライフ (national magazine)
- Kidney Beginnings (e-newsletter)
- Kidney Transplant Today (e-newsletter)
- aakpRENAライフ (e-newsletter)
- At Home with AAKP (e-newsletter)
- AAKP Pediatric Kidney Kids (e-newsletter)
- HealthLine (webinar program)
- HealthLine Innovator (webinar program)
- Cystinosis Patient Scholarship Program
- Patient Safety Award Program
- National High Potassium Awareness Day – “Are You O-K+” campaign (hyperkalemia)
- National Itch Day – “Stop the Itch” campaign (CKD-aP)

For more information on these opportunities and collaborations with AAKP, please contact the following:

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