SUMMARY

Mission

AAKP is a national patient organization dedicated to improving the quality of life of kidney patients through education, advocacy and the fostering of patient communities.

Contact Information

Primary Address
14440 Bruce B. Downs Blvd.
Tampa, FL 33613-
Phone
813 636-8100 1003
Email
info@aakp.org
Website
www.aakp.org
Facebook
kidneypatient
Twitter
KidneyPatients

General Information

Nonprofit
American Association of Kidney Patients, Inc.
Tax Exempt Status
Public Supported Charity
Incorporation Year
1973
State Charitable Solicitations Permit
Yes Mar 2018
State Registration
Yes Mar 2017
BACKGROUND & NEEDS

Impact Statement

• More than 180 visits to Congressional leaders bringing awareness of kidney disease to those who make legislative decision for kidney patients

• Relaunch of the AAKP National Patient Meeting

• Development of the second edition of the AAKP Delicious cookbook – which addressed a long-needed request from patients since diet/nutrition is a major issue for those with kidney disease

• Collaboration with kidney patient organizations and health care professional groups for the revamp of the AAKP National Patient Meeting

• Creation of the Global Needs Survey to help AAKP better understand its constituents (demographics, geographic, needs)

• Increase in public policy efforts in Washington, DC

AAKP has stayed true to the patient voice and is well respected in the renal community and by policy makers for not compromising its core mission which is provide an opportunity for a productive life for all people living with kidney disease.

Needs Statement

1. Increase operating funds
2. Diversify funding sources (donors, corporate funders, foundation grants, etc.)
3. Increase awareness of Organization through a nationally implemented marketing plan (measured by an increase in members and funding support)
4. Increase staff in order to effectively and efficiently meet the Organization’s needs
5. Secure Public Policy lobbyist based in DC to assist Organization stay on top of advocacy issues

Background Statement

The AAKP is the oldest fully independent kidney patient organization in America. For more than 45 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 is a well-known Federal program, familiar across America and within the United States Congress, the End Stage Renal Disease Program administered by the Centers for Medicare and Medicaid Services.

AAKP is governed, by original design and intent, by a patient-majority National Board of Directors. AAKP was founded in 1969 by six kidney patients who were brought together by their disease, the 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. They 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

At the start, these AAKP volunteers – and their compassionate care teams - knew their actions and early engagement would impact not only their own lives, but the lives of patients who they might never meet in the years and decades ahead. However, they also knew that self-less 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 as they moved forward and 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, early leaders in the provider community, and among elected and appointed leaders
throughout government.

After several years of non-partisan advocacy, a bi-partisan majority of the US Congress passed the 1972 Amendments to the Social Security Act. According to the official history of the U.S. Social Security Administration, the 1972 legislative amendments extended health insurance coverage to people who had Chronic Kidney Disease and required dialysis or kidney transplantation services. President Richard M. Nixon signed this bi-partisan measure in 1973 and Federally-covered dialysis treatment and transplantation services for kidney patients began that same year.

Statement from the Board Chair

This year the American Association of Kidney Patients (AAKP) is moving forward to make our patient education materials accessible to more kidney patients, increase our advocacy activities for legislation to improve the quality of life of kidney patients, increase our support of local Kidney patient support groups, and strengthen our Board of Directors. To accomplish this, we are transitioning to free membership for patients and their families, have doubled our patient visits to congressional offices to encourage sponsorship and favorable votes on issues of interest to kidney patients, and are adding a number of new Board members with specific backgrounds to support our new Executive director in implementing our initiatives on behalf of kidney patients.

Continuing to grow funding for our activities in support of kidney patients through donations and grants has been more difficult as a result of more restrictive regulations on corporate grants established a few years ago. This has increased our reliance on the generosity of individual donors who share our passion for improving the quality of life for patients in all stages of kidney disease. We are increasing our focus on raising the awareness of potential individual donors who share this passion.

I became exposed to the AAKP patient educational materials when I found out my kidneys were failing in 1995. They helped me understand my options, calmed my fears about my future, and gave me confidence that I had not lost the potential to live a very full life even when I needed dialysis or was fortunate enough to receive a transplant. I have since been on dialysis for almost 4 years, received a transplant which lasted 12 years, went back on dialysis and 2 years ago received a second transplant. For the over 16 years since my kidney disease diagnosis, I have been able to continue work, travel and visits with my grandchildren. Impressed by the valuable work of AAKP in kidney patient education and advocacy, I joined the AAKP Board of Directors in 2004 in order to give back and help AAKP continue its work in support of people like me. I worked on a number of Board committees before being elected Board President in 2012. AAKP helped me to understand my disease, play an active role in my treatment, and to resist allowing my disease define me and deprive me of many of the joys of life.

Statement from the CEO/Executive Director

Areas Served

Throughout the United States

FL

The American Association of Kidney Patients is a national organization and serves the U.S.

Service Categories

Primary Organization Type
Diseases Disorders & Medical Disciplines

Secondary Organization Type
Education

Tertiary Organization Type
Health Care
<table>
<thead>
<tr>
<th>PROGRAMS</th>
</tr>
</thead>
</table>

**Healthline**

**Description**

HealthLine is currently a webinar-based program (with the conference call option still available for those without a computer) that conveniently educates patients and their family members on a variety of important health care topics from the comfort of their home or office. HealthLine addresses many issues patients with kidney disease face such as diet/nutrition, mention/social/emotional health, medication management, renal replacement treatment options, and co-morbid conditions kidney patients cope with such as hyperparathyroidism, bone disease, anemia, heart disease, and many more.

**Budget**

$50,000.00

**Category**

Diseases, Disorders & Medical Disciplines, General/Other Kidney Diseases

**Program Linked to Organizational Strategy**

Yes

**Population Served**

US & International Other Health/Disability

**Short Term Success**

- First program of its kind for kidney patients
- Since 2007, has educated more than 5,000 patients
- Cost-effective program to implement/execute
- Due to the nature of the program being in webinar format, it is easy to record and archive on AAKP website for continued education for those patients who were unable to participate in the live program
- Since its inception in 2007, AAKP has more than $150,000 in grant funding toward this program

**Long Term Success**

All HealthLine programs are recorded and archived on the AAKP website for sustainability and continued patient education. Each HealthLine webinar attracts approximately 200-300 participants and since the first program in 2006, AAKP has educated more than 5,000 individuals via its HealthLine program.

Based on AAKP collected data from its Global Needs Assessment Survey, 53% of respondents prefer to receive their education through some form of online/web-based educational tool (e.g.; videos, webinars, teleconferences, podcasts, blogs, and emails). This further validates AAKP’s creation of this popular program.

**Program Success Monitoring**

AAKP Director of Programs and Services
Program Success Examples

- Since 2007, has educated more than 5,000 patients
- Approx. 200-300 participants per program
- Survey Data:
  - 80.4% of participants rate the quality of HealthLine as excellent or very good
  - 91.6% of participants would recommend HealthLine to a family member, friend, caregiver or health care professional
  - On average, 42% of U.S. states are represented on each HealthLine program (i.e. – this percentage proves that AAKP is reaching nearly all patients across the U.S.).
  - 55.5% of participants are kidney patients, meaning AAKP is successfully reaching its targeted population
  - 80.5% of participants indicated that by participating in a HealthLine program, they gained more knowledge about the program topic than they originally had
MANAGEMENT

CEO/Executive Director

CEO/Executive Director
Gary Green
CEO Term Start
July 2013
CEO Email
ggreen@aakp.org

Former CEOs/Executive Directors

Kim A Buettner
Sept 2008 - July 2010
Karen Ryals
Aug 2010 - Feb 2013

Senior Staff

Diana Clynes
Director of Programs

Staff & Volunteer Statistics

Full Time Staff 4
Part Time Staff 1
Staff Retention Rate % 90
Professional Development Yes
Contractors 2
Volunteers 25
Management Reports to Board Yes
CEO/Executive Director Formal Evaluation Yes
Senior Management Formal Evaluation Yes
NonManagement Formal Evaluation Yes

Collaborations


Comments
GOVERNANCE

Board Chair

**Board Chair**  
Paul T. Conway

**Company Affiliation**  
Board Member

**Board Term**  
Sept 2014 to Sept 2016

**Board Chair Email**  
paulconway@cox.net

Board Members

<table>
<thead>
<tr>
<th>Name</th>
<th>Affiliation</th>
<th>Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Daniel L Abel</td>
<td>Board Member</td>
<td>Voting</td>
</tr>
<tr>
<td>Teri Browne PhD</td>
<td>Board Member</td>
<td>Voting</td>
</tr>
<tr>
<td>Paul T Conway</td>
<td>Community Volunteer</td>
<td>Voting</td>
</tr>
<tr>
<td>Dr Tejas Desai</td>
<td>Board Member</td>
<td>Voting</td>
</tr>
<tr>
<td>Dr. Louis H. Diamond</td>
<td>Quality Health Care</td>
<td>Voting</td>
</tr>
<tr>
<td>Lisa Garner</td>
<td>Independent Living</td>
<td>Voting</td>
</tr>
<tr>
<td>Theodore Gee Jr.</td>
<td>Lean Leaders</td>
<td>Voting</td>
</tr>
<tr>
<td>Dr Richard Goldman</td>
<td>Nephrologist and Community Volunteer</td>
<td>Voting</td>
</tr>
<tr>
<td>Dr. Raymond M. Hakim</td>
<td>Vanderbilt University School of Medicine</td>
<td>Voting</td>
</tr>
<tr>
<td>Brian Hess</td>
<td>Patient Advocate</td>
<td>Voting</td>
</tr>
<tr>
<td>Jenny Kitsen</td>
<td>Patient Advocate</td>
<td>Voting</td>
</tr>
<tr>
<td>Richard Knight</td>
<td>Community Volunteer</td>
<td>Voting</td>
</tr>
<tr>
<td>Tanya Langford JD</td>
<td>University of Tampa</td>
<td>Voting</td>
</tr>
<tr>
<td>Dr Robert B Miller</td>
<td>Board Member</td>
<td>Voting</td>
</tr>
<tr>
<td>Sam Pederson</td>
<td>Community Volunteer</td>
<td>Voting</td>
</tr>
<tr>
<td>Gigi Politoski</td>
<td>Patient Advocate</td>
<td>Voting</td>
</tr>
<tr>
<td>Suzanne Ruff</td>
<td>Patient Advocate</td>
<td>Voting</td>
</tr>
<tr>
<td>Lana Schmidt</td>
<td>Patient Advocate</td>
<td>Voting</td>
</tr>
<tr>
<td>Scott Toner</td>
<td>Board Member</td>
<td>Voting</td>
</tr>
<tr>
<td>Linda S Tyler</td>
<td>Board Member</td>
<td>Voting</td>
</tr>
<tr>
<td>Linda Umbach</td>
<td>Board Member</td>
<td>Voting</td>
</tr>
</tbody>
</table>

Board Demographics - Ethnicity

- **African American/Black**: 3
- **Asian American/Pacific Islander**: 1
- **Caucasian**: 16
- **Hispanic/Latino**: 0
- **Native American/American Indian**: 0
- **Other**: 0 (India)
Board Demographics - Gender

<table>
<thead>
<tr>
<th>Gender</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>11</td>
</tr>
<tr>
<td>Female</td>
<td>9</td>
</tr>
<tr>
<td>Not Specified</td>
<td>0</td>
</tr>
</tbody>
</table>

Governance

<table>
<thead>
<tr>
<th>Governance</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Board Term Lengths</td>
<td>3</td>
</tr>
<tr>
<td>Board Term Limits</td>
<td>3</td>
</tr>
<tr>
<td>Board Orientation</td>
<td>Yes</td>
</tr>
<tr>
<td>Number of Full Board Meetings Annually</td>
<td>4</td>
</tr>
<tr>
<td>Board Meeting Attendance %</td>
<td>82</td>
</tr>
<tr>
<td>Board Self-Evaluation</td>
<td>No</td>
</tr>
<tr>
<td>Written Board Selection Criteria</td>
<td>No</td>
</tr>
<tr>
<td>Percentage of Board Making Monetary Contributions</td>
<td>66</td>
</tr>
<tr>
<td>Percentage of Board Making In-Kind Contributions</td>
<td>100</td>
</tr>
<tr>
<td>Constituency Includes Client Representation</td>
<td>Yes</td>
</tr>
</tbody>
</table>

Standing Committees

- Executive
- Program / Program Planning
- Finance
- Nominating
- Program / Program Planning
- Development / Fund Development / Fund Raising / Grant Writing / Major Gifts
- Legislative
- Communications / Promotion / Publicity / Public Relations
Current Financial Info

- Fiscal Year Begins: 2015
- Fiscal Year Ends: 2016
- Projected Revenue: $844,720.00
- Projected Expenses: $804,600.00
- Endowment Value: $0.00
- Spending Policy: N/A
- Spending Policy Percentage: 0
- Tax Credits: No

Capital Campaign

- In a Capital Campaign: No
- Campaign Goal: 0

IRS Form 990s

- Form 990
- Form 990
- 990 2013-2014
- 990 2012-2013
- AAKP 990
- AAKP 990
- AAKP 990
- Form 990
- Form 990

Audit/Financial Documents

- Audit 2013-2014
- Audit 2012-2013
- AAKP AUDIT 2011-2012
- AAKP AUDIT 2009-2010

Solvency

<table>
<thead>
<tr>
<th>Short Term Solvency</th>
<th>2016</th>
<th>2015</th>
<th>2014</th>
</tr>
</thead>
<tbody>
<tr>
<td>Current Ratio: Current Assets/Current Liabilities</td>
<td>1.59</td>
<td>2.35</td>
<td>1.62</td>
</tr>
</tbody>
</table>

Long Term Solvency
### Fiscal Year

<table>
<thead>
<tr>
<th></th>
<th>2016</th>
<th>2015</th>
<th>2014</th>
</tr>
</thead>
<tbody>
<tr>
<td>Long-Term Liabilities/Total Assets</td>
<td>0%</td>
<td>0%</td>
<td>4%</td>
</tr>
</tbody>
</table>

### Historical Financial Review

#### Revenue and Expenses

<table>
<thead>
<tr>
<th>Fiscal Year</th>
<th>2016</th>
<th>2015</th>
<th>2014</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Revenue</td>
<td>$793,302</td>
<td>$663,192</td>
<td>$710,588</td>
</tr>
<tr>
<td>Total Expenses</td>
<td>$783,235</td>
<td>$737,383</td>
<td>$700,409</td>
</tr>
</tbody>
</table>

#### Revenue Sources

<table>
<thead>
<tr>
<th>Fiscal Year</th>
<th>2016</th>
<th>2015</th>
<th>2014</th>
</tr>
</thead>
<tbody>
<tr>
<td>Foundation and Corporation Contributions</td>
<td>$0</td>
<td>$0</td>
<td>$0</td>
</tr>
<tr>
<td>Government Contributions</td>
<td>$0</td>
<td>$0</td>
<td>$0</td>
</tr>
<tr>
<td>Federal</td>
<td>$0</td>
<td>$0</td>
<td>$0</td>
</tr>
<tr>
<td>State</td>
<td>$0</td>
<td>$0</td>
<td>$0</td>
</tr>
<tr>
<td>Local</td>
<td>$0</td>
<td>$0</td>
<td>$0</td>
</tr>
<tr>
<td>Unspecified</td>
<td>$0</td>
<td>$0</td>
<td>$0</td>
</tr>
<tr>
<td>Individual Contributions</td>
<td>$481,627</td>
<td>$452,419</td>
<td>$584,793</td>
</tr>
<tr>
<td>Indirect Public Support</td>
<td>$0</td>
<td>$8,965</td>
<td>$8,707</td>
</tr>
<tr>
<td>Earned Revenue</td>
<td>$270,268</td>
<td>$138,386</td>
<td>$428,533</td>
</tr>
<tr>
<td>Investment Income, Net of Losses</td>
<td>$0</td>
<td>$59</td>
<td>$455</td>
</tr>
<tr>
<td>Membership Income</td>
<td>$8,580</td>
<td>$8,205</td>
<td>$6,680</td>
</tr>
<tr>
<td>Special Events</td>
<td>$28,028</td>
<td>$52,543</td>
<td>$57,161</td>
</tr>
<tr>
<td>Revenue In-Kind</td>
<td>$6,119</td>
<td>$13,767</td>
<td>$9,263</td>
</tr>
<tr>
<td>Other</td>
<td>$4,799</td>
<td>$2,615</td>
<td>$9,939</td>
</tr>
</tbody>
</table>

#### Expense Allocation

<table>
<thead>
<tr>
<th>Fiscal Year</th>
<th>2016</th>
<th>2015</th>
<th>2014</th>
</tr>
</thead>
<tbody>
<tr>
<td>Program Expense</td>
<td>$594,649</td>
<td>$531,887</td>
<td>$501,711</td>
</tr>
<tr>
<td>Administration Expense</td>
<td>$160,944</td>
<td>$163,088</td>
<td>$165,830</td>
</tr>
<tr>
<td>Fundraising Expense</td>
<td>$27,642</td>
<td>$42,408</td>
<td>$32,868</td>
</tr>
<tr>
<td>Payments to Affiliates</td>
<td>$0</td>
<td>$0</td>
<td>$0</td>
</tr>
<tr>
<td>Total Revenue/Total Expenses</td>
<td>1.01</td>
<td>0.90</td>
<td>1.01</td>
</tr>
<tr>
<td>Program Expense/Total Expenses</td>
<td>76%</td>
<td>72%</td>
<td>72%</td>
</tr>
<tr>
<td>Fundraising Expense/Contributed Revenue</td>
<td>5%</td>
<td>8%</td>
<td>5%</td>
</tr>
</tbody>
</table>

#### Assets and Liabilities

<table>
<thead>
<tr>
<th>Fiscal Year</th>
<th>2016</th>
<th>2015</th>
<th>2014</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Assets</td>
<td>$296,261</td>
<td>$176,449</td>
<td>$493,360</td>
</tr>
<tr>
<td>Current Assets</td>
<td>$292,686</td>
<td>$175,468</td>
<td>$484,802</td>
</tr>
<tr>
<td>Long-Term Liabilities</td>
<td>$0</td>
<td>$0</td>
<td>$18,030</td>
</tr>
<tr>
<td>Current Liabilities</td>
<td>$184,333</td>
<td>$74,588</td>
<td>$299,278</td>
</tr>
<tr>
<td>Total Net Assets</td>
<td>$111,928</td>
<td>$101,861</td>
<td>$176,052</td>
</tr>
</tbody>
</table>

#### Top Funding Sources

<table>
<thead>
<tr>
<th>Fiscal Year</th>
<th>2016</th>
<th>2015</th>
<th>2014</th>
</tr>
</thead>
<tbody>
<tr>
<td>Top Funding Source &amp; Dollar Amount</td>
<td>Contributions, gifts, grants $481,627</td>
<td>Contributions, gifts, grants $452,419</td>
<td>Contributions, gifts, grants $584,793</td>
</tr>
<tr>
<td>Second Highest Funding Source &amp; Dollar Amount</td>
<td>Annual Meeting Fees $188,234</td>
<td>Annual meeting fees $111,897</td>
<td>Fundraising $57,161</td>
</tr>
<tr>
<td>Third Highest Funding Source &amp; Dollar Amount</td>
<td>Advertising Sales $50,591</td>
<td>Fundraising $52,543</td>
<td>Brochure and magazine sales $42,853</td>
</tr>
</tbody>
</table>
Comments

**Financial Comments by Foundation**
Financial information taken from IRS Form 990 and audit documents, where provided. Individual contributions include foundation and corporate support. Federal tax returns reconcile with audited financial statements provided.
PLANS, POLICIES & LICENSES

Plans

- Fundraising Plan: No
- Communication Plan: No
- Strategic Plan: No
- Strategic Plan Adopted: July 2012
- Years Strategic Plan Considers: 3
- Management Succession Plan: No
- Continuity of Operations Plan: No

Policies

- Organizational Policies and Procedures: Yes
- Written Conflict of Interest Policy: Yes
- Nondiscrimination Policy: Yes
- Directors and Officers Insurance Policy: No
- Risk Management Policy:
  Commercial General Liability and D and O and Umbrella or Excess and Automobile and Professional
  Workers Compensation and Employers' Liability
- Whistle Blower Policy: Yes
- Document Destruction Policy: No

Government Licenses

- Is your organization licensed by the Government? No

Planning & Policies Comments

- Planning & Policies Comments by Organization
- Planning & Policies Comments by Foundation