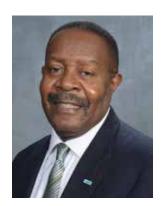




WELCOME TO THE 2019 NATIONAL PATIENT MEETING



Richard Knight
President
American Association of
Kidney Patients

It is my honor, on behalf of the AAKP Board of Directors, to welcome you to our 44th Annual National Patient Meeting. The meeting this year takes place during AAKP's 50th Anniversary. You are a member of the oldest and largest fully independent patient-led kidney organization in the United States. Patients founded AAKP with the mission of educating and advocating. By attending this Annual Event, you will partake in one of the most educational undertakings offered by kidney patients for kidney patients in the United States. You will also get updates on legislative initiatives that will help you become a better advocate for yourself and fellow patients on kidney issues.

AAKP continues to follow its National Strategy that builds on education, advocacy, and patient engagement. We do not react; we are proactive; by involvement in significant initiatives that happen along the kidney continuum – we, patients, have a seat at the table. This year is no different – from the early stages of chronic kidney disease (CKD) to dialysis, to transplantation – AAKP played a role in several initiatives that have occurred since our last gathering, including the President's Executive Order – Advancing American Kidney Health.

The hard work done by this year's Convention Planning Committee has produced a program truly worthy of AAKP's 50th Anniversary. The Committee has pulled together a Convention that reflects many of the changes that have taken place during the past twelve months. The Committee strived to construct a program that will inform each of you not just about changes in the kidney arena, but the implication of changes on patients. Convention sessions include Changing the National Landscape in Kidney Care; Technology and Developments that Impact Your Care; Patient-Centered Research: Shaping the Future of Your Care, and the ever-popular Under the U.S. Capitol Dome.

AAKP's members are actively engaged in social media. Let's continue to use social media as a way to educate and advocate for each other. Please take advantage of the Social Media Center while you are at the Convention by liking us on Facebook and following us on Twitter. During the Convention, use the hashtag **#KidneyPatients19**.

From the entire AAKP Board of Directors and professional staff, we thank you for joining us in the nation's capital – Washington, D.C.



Lisa GarnerNational Board of Directors,
American Association of Kidney Patients
2019 Convention Program Chair

We are celebrating 50 Golden Years at this year's 2019 American Association of Kidney Patients National Patient Meeting! We have gone back to our roots of where it all started in beautiful and historic Washington, D.C. AAKP has always been about bringing education, advocacy and community to kidney patients, their families and their caregivers. This year is no different! There will be three days of informative sessions that are designed with you in mind. Don't miss our Lunch with the Experts! I have always found this to be an exciting way to meet fellow patients from all over and learn valuable information on a wide range of topics. It's hard to just choose just one, great thing is you get to choose two!

AAKP has provided an exhibit hall with vendors that have resources to help you in your kidney journey. There will also be focus groups that will be stationed between sessions hosted by our industry and allied partners, aimed at hearing the true, independent patient voice on topics important to you. Be sure to join us Saturday night for the AAKP Annual Awards banquet honoring AAKP members and other distinguished volunteers and representatives throughout the kidney community. Stay in tune with social media and share your experience using conference hashtag **#KidneyPatients19** on Twitter, Facebook and Instagram. Thank you again for coming to our 50th Anniversary Celebration National Patient Meeting and for your continued support of AAKP!

American Association of Kidney Patients 2019 National Board of Directors



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General Information

Registration Center

The AAKP Registration Booth is located at the **Ballroom Level**, **Regency B** foyer area. Attendees can check-in and receive their name badge, tote bag and materials at this location.

Registration Booth hours are:

Thursday, September 5 1:00 p.m. - 5:00 p.m.

Friday, September 6 7:00 a.m. - 4:00 p.m.

Saturday, September 7 7:00 a.m. - 4:00 p.m.

Sunday, September 8 7:30 a.m. - 12:00 p.m.

Exhibitors

The Exhibit Hall is located in Regency BCD on the Ballroom Level. The Exhibit Hall features a variety of kidney-related companies and organizations. Registration badges are required for entry. Continental breakfast will be served in the exhibit hall on Friday, Saturday and Sunday.

Exhibit Hall hours are:

Friday, September 6

7:00 a.m. - 8:30 a.m.

4:30 p.m. - 6:30 p.m.

Saturday, September 7

7:00 a.m. - 9:00 a.m.

3:30 p.m. - 5:30 p.m.

Sunday, September 8 7:30 a.m. - 9:00 a.m.

Social Media Center

The Social Media Center is located inside the Exhibit Hall. This lounge area allows guests to charge up their devices while relaxing. Water and light snacks will be available. While you are there, don't forget to use our fun props to post to your social media pages using #KidneyPatients19 and tagging AAKP on Twitter & Instagram @kidneypatients and on Facebook @kidneypatient.

Additionally, we have an exhibit hall passport for you to check off which exhibits you visited, as well as a social media game that we encourage all attendees to take part in. Copies of the passport and game will be available in your totebag as well as at the Social Media Center.

Special thanks to **Retrophin** for sponsoring the Social Media Center.

Wellness Center

The Wellness Center, located in the Exhibit Hall, offers guests free health screens provided by **Black Nurses Rock DMV Chapter**. Health screening tables including blood pressure and finger prick will be available.

Awards Dinner Banquet

Come dressed to impress! This elegant evening will feature special presentations and recognize AAKP National Award Winners. The evening will include socializing, dinner and dessert with a DJ and dancing to celebrate AAKP's 50th Anniversary.

Wi-Fi

Wi-Fi will be available throughout the event. Special thanks to **Amgen** for sponsoring WiFi at the AAKP National Patient Meeting! Passcode: **AMGEN2019**

Food

AAKP strives to provide meals that are acceptable to CKD, dialysis and transplant patients. AAKP recognizes that many attendees have modified diets; however, it is the attendee's responsibility to make appropriate food choices and consume only those food items offered that are appropriate for their diet.

CAPD Exchanges

Peritoneal dialysis exchanges can be done in a separate AAKP room. Please see an AAKP staff member at the registration booth for more information.

Dialysis Arrangements

For questions regarding your dialysis arrangements, please visit the registration booth or reference the appointment information provided to you by your dialysis clinic.

CE Credits

Credits are offered to nurses, social workers, and dialysis technicians pending approval of accrediting agencies. Certificates of Attendance are also available for other healthcare professionals. To receive credit for attending sessions; you MUST sign-in and sign-out each day at the registration booth and return a completed evaluation form. Please see the registration booth for more information.





AAKP Meeting Agenda

Black - General Session / Blue - Breakout Session A / Green - Breakout Session B / Red - Breakout Session C *Agenda may be subject to change

| TIME | EVENT / SESSION | | |
|------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--|--|
| FRIDAY, SEPTEMBER 6 | EVENT/OCCOLON- | | |
| 7:00 a.m. – 4:00 p.m. | | | |
| Regency, Foyer Area | Registration | | |
| 7:00 a.m. – 8:30 a.m. Regency BCD, Ballroom Level | Exhibit Hall Open/Continental Breakfast | | |
| 8:30 a.m. – 8:45 a.m. | Convention Welcome | | |
| Regency A, Ballroom Level | Richard Knight, AAKP President | | |
| 8:45 a.m. – 9:15 a.m. Regency A, Ballroom Level | General Session: Changing the National Landscape of Kidney Care | | |
| 9:15 a.m. – 10:15 a.m. Regency A, Ballroom Level | General Session: Patient Engagement & Federal Cabinet Agencies - Opportunities to Serve Your Fellow Patients Patricia Modrow, MD, U.S. Department of Defense; Christine Schott, U.S. Department of Labor; Paul Kimmell, MD, MACP, National Institutes of Health; Jesse Roach, MD, Centers for Medicare and Medicaid Services This session is proudly supported by Amgen, Inc. | | |
| 10:15 a.m. – 11:15 a.m. Regency A, Ballroom Level | General Session: Trending Today: Technology and Developments that Impact Your Care Kenneth Newell, PhD, MD, Emory University; Reginald Seeto, MD, MBBS, President, CBO, CareDx; Joe Muldoon, CEO, FAST BioMedical | | |
| 11:15 a.m. – 12:15 p.m. Regency A, Ballroom Level | General Session: Advancements in Kidney Care: What the Future Holds Bruce Culleton, MD, VP, CMO, Kidney Care at CVS Health; Ramon Mendez, MD, FASN, FACP, VP of Medical Affairs, Somatus; William Fissell, MD, Associate Professor, Vanderbilt University, Medical Director of The Kidney Project | | |
| 12:15 p.m. – 12:30 p.m. | Health Break | | |
| 12:30 p.m. – 1:30 p.m. Congressional AB, Lobby Level | Lunch with the Experts (see list of table topics on page 8) | | |
| 1:30 p.m. – 1:45 p.m. | Health Break | | |
| Breakout Sessions | | | |
| 1:45 p.m. – 2:30 p.m. Regency A, Ballroom Level | Breakout Session A: Advancements in Diabetes Management Dominic Raj, MD, DM, FASN, George Washington University School of Medicine and Health Sciences | | |
| 1:45 p.m. – 2:30 p.m. Lexington/Bunkerhill, Ballroom Level | Breakout Session B: Transplant First: Understanding Pre-emptive Transplantation Kenneth Newell, MD, PhD, Professor of Surgery, Division of Transplantation, Department of Surgery, Emory University School of Medicine, Risa Simon, AAKP Ambassador, Pre-emptive transplant recipient, Founder of Transplant First Academy. This session is proudly supported by CareDx, Inc. | | |
| 1:45 p.m. – 2:30 p.m. Concord, Ballroom Level | Breakout Session C: The Connection between Heart Disease and Kidney Disease Akhtar Ashfaq, MD, Senior Vice President, Clinical Research & Development and Medical Affairs, OPKO Renal This session is proudly supported by Amgen, Inc. | | |
| 2:30 p.m. – 2:45 p.m. | Health Break | | |
| Breakout Sessions | | | |
| 2:45 p.m. – 3:30 p.m. Regency A, Ballroom Level | Breakout Session A: An Update on Hypertension Management Stephen Fadem, MD, FASN, FACP, Chair of AAKP Medical Advisory Board, Kidney Associates, PLLC, Clinical Professor at Baylor College of Medicine | | |
| 2:45 p.m. – 3:30 p.m. Lexington/Bunkerhill, Ballroom Level | Breakout Session B: KidneyWorks: Employment Options and Programs Renee Bova-Collis, MSW, LCSW, Patient Services Director, Mid-Atlantic Renal Coalition; Bruce Tippets, AAKP Ambassador | | |
| 2:45 p.m. – 3:30 p.m. Concord, Ballroom Level | Breakout Session C: Understanding Acute Kidney Injury and Possible Long-term Effects Ashte Collins, MD, Assistant Professor of Medicine, George Washington University School of Medicine and Health Sciences | | |
| 3:30 p.m. – 3:45 p.m. | Health Break | | |
| 3:45 p.m. – 4:30 p.m. | Breakout Sessions | | |
| Regency A, Ballroom Level | Breakout Session A: Infection Prevention: Staying Healthy In & Out of the Dialysis Facility Priti Patel, MD, MPH, Centers for Disease Control and Prevention; Melissa Bensouda, AAKP Ambassador | | |
| Lexington/Bunkerhill, Ballroom Level | Breakout Session B: Choosing and Changing Renal Replacement Therapies - Peer Mentorship (Featured PCOR Track) Janice Lea, MD, Emory University, AAKP Board of Director | | |
| Concord, Ballroom Level | Breakout Session C: Emergency Management & Kidney Disease: Manmade and Natural Disasters Kerry Leigh, BSN, RN, Project Specialist, Nephrologists Transforming Dialysis Safety, ASN Alliance for Kidney Health | | |
| 4:30 p.m. – 6:30 p.m. Regency BCD, Ballroom Level | Exhibit Hall Open/Welcome Reception | | |

| 7:00 a.m. – 4:00 p.m. | | | |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--|--|
| | Registration | | |
| Regency, Foyer Area | Registration | | |
| 7:00 a.m. – 9:00 a.m. Regency BCD, Ballroom Level | Exhibit Hall Open/Continental Breakfast | | |
| 9:00 a.m. – 10:00 a.m. | General Session: Under the U.S. Capitol Dome | | |
| Regency A, Ballroom Level | Robert Blaser, Director of Public Policy, Renal Physicians Association; | | |
| Negericy A, Barroom Lever | Peggy Tighe, Principal, Government/Legislative, American Society of Transplant Surgeons | | |
| 10:00 a.m. – 10:15 a.m. | Health Break | | |
| Breakout Sessions | | | |
| 0:15 a.m. – 11:00 a.m. | Breakout Session A: Raise Your Voice: The Power of Social Media and Grassroots Tactics | | |
| Regency A, Ballroom Level | Paul T. Conway, AAKP Chair of Policy & Global Affairs; Jim Myers, AAKP Board of Director, Ambassador | | |
| 10:15 a.m. – 11:00 a.m. | Breakout Session B: AAKP Pediatric Kidney Pals: Caring for Young Patients | | |
| Congressional A, Lobby Level | Jack Lennon, MBA, BSBA and Brian Hess, AAKP Board Member | | |
| 10:15 a.m. – 11:00 a.m. | Breakout Session C: Patient Perspectives in Gout (Horizon Sponsored Session) | | |
| Congressional B, Lobby Level | Brian LaMoreaux, MD, Medical Director, Horizon Therapeutics | | |
| 11:00 a.m. – 11:15 a.m. | Health Break | | |
| Breakout Sessions | | | |
| | Breakout Session A: AAKP Going Global: Ambassador Initiatives | | |
| 11:15 a.m. – 12:00 p.m. | Erin Kahle, AAKP Director of Stakeholder Operations; Dale Rogers, AAKP Ambassador; | | |
| Regency A, Ballroom Level | David Rodriguez, AAKP Board of Director, Ambassador | | |
| 11:15 a.m. – 12:00 p.m. | Breakout Session B: Plant-based Nutrition and Kidney Disease | | |
| Congressional A, Lobby Level | Jennifer Moore, MS, RDN, CSR, LDN | | |
| 11:15 a.m. – 12:00 p.m. | Breakout Session C: Innovations in Vascular Access (Humacyte Sponsored Session) | | |
| Congressional B, Lobby Level | Jeffrey Lawson, MD, PhD, President & CEO, Humacyte; Julianna Blum, PhD, Co-founder, Humacyte | | |
| 12:00 p.m. – 12:15 p.m. | Health Break | | |
| 12:15 p.m. – 1:15 p.m. | Health Dreak | | |
| Congressional AB, Lobby Level | Lunch with the Experts (see list of table topics on page 9) | | |
| | Health Break | | |
| 1:15 p.m. – 1:30 p.m. | Health Break | | |
| Breakout Sessions | | | |
| 1:30 p.m. – 2:15 p.m. | Breakout A: Activating Patients and Partners to Accelerate Kidney Transplantation | | |
| Regency A, Ballroom Level | Lisa Plummer, RN, Centers for Medicare and Medicaid Services; Renee Dupee, Centers for Medicare | | |
| | and Medicaid Services | | |
| 1:30 p.m. – 2:15 p.m. | Breakout Session B: Understanding Genetic Conditions in Kidney Disease | | |
| Congressional A, Lobby Level | Scott Cohen, MD, George Washington University School of Medicine and Health Sciences | | |
| 1:30 p.m. – 2:15 p.m. | Breakout Session C: The Importance of Dental Health for Kidney Patients | | |
| Congressional B, Lobby Level | Cheryl Thomas, RDH | | |
| 2:15 p.m. – 2:30 p.m. | Health Break | | |
| Breakout Sessions | | | |
| | | | |
| 2:30 p.m. – 3:15 p.m. | Breakout Session A: Understanding Phosphate Management in Kidney Disease: The HiLo Study | | |
| | Breakout Session A: Understanding Phosphate Management in Kidney Disease: The HiLo Study Myles Wolf, MD, Duke University | | |
| Regency A, Ballroom Level | Myles Wolf, MD, Duke University | | |
| Regency A, Ballroom Level 2:30 p.m. – 3:15 p.m. | Myles Wolf, MD, Duke University Breakout Session B: Building a Local and Online Community | | |
| Regency A, Ballroom Level 2:30 p.m. – 3:15 p.m. Congressional A, Lobby Level | Myles Wolf, MD, Duke University Breakout Session B: Building a Local and Online Community Sharron Rouse, AAKP Ambassador and Jennifer Jones, AAKP Ambassador | | |
| Regency A, Ballroom Level 2:30 p.m. – 3:15 p.m. Congressional A, Lobby Level 2:30 p.m. – 3:15 p.m. | Myles Wolf, MD, Duke University Breakout Session B: Building a Local and Online Community Sharron Rouse, AAKP Ambassador and Jennifer Jones, AAKP Ambassador Breakout Session C: Living Donor Issues | | |
| Regency A, Ballroom Level 2:30 p.m. – 3:15 p.m. Congressional A, Lobby Level 2:30 p.m. – 3:15 p.m. Congressional B, Lobby Level | Myles Wolf, MD, Duke University Breakout Session B: Building a Local and Online Community Sharron Rouse, AAKP Ambassador and Jennifer Jones, AAKP Ambassador Breakout Session C: Living Donor Issues Jonathan Gill, MD, MS, University of British Columbia | | |
| Regency A, Ballroom Level 2:30 p.m. – 3:15 p.m. Congressional A, Lobby Level 2:30 p.m. – 3:15 p.m. Congressional B, Lobby Level 3:30 p.m. – 5:30 p.m. | Myles Wolf, MD, Duke University Breakout Session B: Building a Local and Online Community Sharron Rouse, AAKP Ambassador and Jennifer Jones, AAKP Ambassador Breakout Session C: Living Donor Issues | | |
| Regency A, Ballroom Level 2:30 p.m. – 3:15 p.m. Congressional A, Lobby Level 2:30 p.m. – 3:15 p.m. Congressional B, Lobby Level 3:30 p.m. – 5:30 p.m. Regency BCD, Ballroom Level | Myles Wolf, MD, Duke University Breakout Session B: Building a Local and Online Community Sharron Rouse, AAKP Ambassador and Jennifer Jones, AAKP Ambassador Breakout Session C: Living Donor Issues Jonathan Gill, MD, MS, University of British Columbia Exhibit Hall Open | | |
| Regency A, Ballroom Level 2:30 p.m. – 3:15 p.m. Congressional A, Lobby Level 2:30 p.m. – 3:15 p.m. Congressional B, Lobby Level 3:30 p.m. – 5:30 p.m. Regency BCD, Ballroom Level 6:00 p.m. – 9:00 p.m. | Myles Wolf, MD, Duke University Breakout Session B: Building a Local and Online Community Sharron Rouse, AAKP Ambassador and Jennifer Jones, AAKP Ambassador Breakout Session C: Living Donor Issues Jonathan Gill, MD, MS, University of British Columbia | | |
| Regency A, Ballroom Level 2:30 p.m. – 3:15 p.m. Congressional A, Lobby Level 2:30 p.m. – 3:15 p.m. Congressional B, Lobby Level 3:30 p.m. – 5:30 p.m. Regency BCD, Ballroom Level 6:00 p.m. – 9:00 p.m. Regency A, Ballroom Level | Myles Wolf, MD, Duke University Breakout Session B: Building a Local and Online Community Sharron Rouse, AAKP Ambassador and Jennifer Jones, AAKP Ambassador Breakout Session C: Living Donor Issues Jonathan Gill, MD, MS, University of British Columbia Exhibit Hall Open | | |
| Regency A, Ballroom Level 2:30 p.m. – 3:15 p.m. Congressional A, Lobby Level 2:30 p.m. – 3:15 p.m. Congressional B, Lobby Level 3:30 p.m. – 5:30 p.m. Regency BCD, Ballroom Level 5:00 p.m. – 9:00 p.m. Regency A, Ballroom Level SUNDAY, SEPTEMBER 8 | Myles Wolf, MD, Duke University Breakout Session B: Building a Local and Online Community Sharron Rouse, AAKP Ambassador and Jennifer Jones, AAKP Ambassador Breakout Session C: Living Donor Issues Jonathan Gill, MD, MS, University of British Columbia Exhibit Hall Open AAKP Annual Awards Banquet (dinner served, entertainment) | | |
| Regency A, Ballroom Level 2:30 p.m. – 3:15 p.m. Congressional A, Lobby Level 2:30 p.m. – 3:15 p.m. Congressional B, Lobby Level 3:30 p.m. – 5:30 p.m. Regency BCD, Ballroom Level 6:00 p.m. – 9:00 p.m. Regency A, Ballroom Level SUNDAY, SEPTEMBER 8 7:30 a.m. – 12:00 p.m. | Myles Wolf, MD, Duke University Breakout Session B: Building a Local and Online Community Sharron Rouse, AAKP Ambassador and Jennifer Jones, AAKP Ambassador Breakout Session C: Living Donor Issues Jonathan Gill, MD, MS, University of British Columbia Exhibit Hall Open | | |
| 2:30 p.m. – 3:15 p.m. Regency A, Ballroom Level 2:30 p.m. – 3:15 p.m. Congressional A, Lobby Level 2:30 p.m. – 3:15 p.m. Congressional B, Lobby Level 3:30 p.m. – 5:30 p.m. Regency BCD, Ballroom Level 6:00 p.m. – 9:00 p.m. Regency A, Ballroom Level SUNDAY, SEPTEMBER 8 7:30 a.m. – 12:00 p.m. Regency, Foyer Area 7:30 a.m. – 9:00 a.m. | Myles Wolf, MD, Duke University Breakout Session B: Building a Local and Online Community Sharron Rouse, AAKP Ambassador and Jennifer Jones, AAKP Ambassador Breakout Session C: Living Donor Issues Jonathan Gill, MD, MS, University of British Columbia Exhibit Hall Open AAKP Annual Awards Banquet (dinner served, entertainment) Registration | | |
| Regency A, Ballroom Level 2:30 p.m. – 3:15 p.m. Congressional A, Lobby Level 2:30 p.m. – 3:15 p.m. Congressional B, Lobby Level 3:30 p.m. – 5:30 p.m. Regency BCD, Ballroom Level 6:00 p.m. – 9:00 p.m. Regency A, Ballroom Level SUNDAY, SEPTEMBER 8 7:30 a.m. – 12:00 p.m. Regency, Foyer Area | Myles Wolf, MD, Duke University Breakout Session B: Building a Local and Online Community Sharron Rouse, AAKP Ambassador and Jennifer Jones, AAKP Ambassador Breakout Session C: Living Donor Issues Jonathan Gill, MD, MS, University of British Columbia Exhibit Hall Open AAKP Annual Awards Banquet (dinner served, entertainment) | | |

| 7:30 a.m. – 12:00 p.m. | Registration | |
|------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--|
| Regency, Foyer Area | | |
| 7:30 a.m. – 9:00 a.m. | Exhibit Hall Open/Continental Breakfast | |
| Regency BCD, Ballroom Level | ' | |
| 9:15 a.m. – 10:15 a.m. Regency A, Ballroom Level | General Session: Patient-Centered Research: Shaping the Future of Your Care (Featured PCOR Track) Sara Traigle van Geertruyden, JD, Partnership to Improve Patient Care; Janice Lea, MD, Emory University, AAKP Board of Director; David White, AAKP Board of Director | |
| 10:15 a.m. – 11:15 a.m. Regency A, Ballroom Level | General Session: AAKP Action Alert 2020 | |
| 11:15 a.m. – 11:30 p.m. Regency A, Ballroom Level | Closing Remarks | |

Friday's Lunch with the Experts Location: Lobby Level, Congressional AB

| Table 1 | The Kidney Project: Artificial Implantable Kidney | William Fissel, MD |
|----------|-------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------|
| Table 2 | Overcoming Barriers to Transplantation | Muralidharan Jagadeesan, MD, FACP, FASN |
| Table 3 | Transplant Before Dialysis: Is It Possible? | Kenneth Newell, PhD, MD |
| Table 4 | Building an Active Kidney Community in Your Area | Sharron Rouse, AAKP Ambassador |
| Table 5 | Communicating with Your Healthcare Team: How to Be Your Own Best Advocate | Nancy Uhland, FNP |
| Table 6 | Your New Normal: Life After Transplant | Odette Ntam, RN |
| Table 7 | Lunch with AAKP President | Richard Knight, AAKP President |
| Table 8 | Advocating and Caring for Young Patients | Jack Lennon, MBA, BSBA, AAKP Ambassador |
| Table 9 | AAKP Veterans Health Initiative: What Resources are Available to Veterans? | Edward Hickey, Chair AAKP Veterans Health Initiative & Kent Bressler, AAKP Board of Director, Ambassador |
| Table 10 | Cooking Kidney-Friendly | Carolyn Feibig, MS, RD, LD |
| Table 11 | Avoiding Caregiver Burnout: Taking Time to Take Care of Yourself | Sherri Thomas, AAKP Ambassador |
| Table 12 | Balancing It All: Family, Work, and Kidney Disease | Alana Hunnicutt-Carroll, AAKP Ambassador |
| Table 13 | Healthy and Creative Ways to Cope with a Chronic Illness | Austin Lee, AAKP Ambassador |
| Table 14 | Simple Ways to Stay Active with Kidney Disease | Tanya Clark |
| Table 15 | Is Home Dialysis Right for Me? | Ramon Mendez, MD |
| Table 16 | Is a Plant-based Diet Right for Me? | Jennifer Moore, MS, RDN, CSR, LDN |
| Table 17 | Living with a Rare Disease or Condition | Sherry Dadgar, MD, PhD |
| Table 18 | Building Relationships with Elected Officials | Brian Hess, AAKP Board of Director |
| Table 19 | Patient-Centered Research: Making Your Voice Heard (Featured PCOR Track) | David White, AAKP Board of Director, Ambassador |
| Table 20 | What Does it Mean to be Involved in a Clinical Trial? | Janice Lea, MD, AAKP Board of Director |
| Table 21 | How to Find a Living Donor: Sharing Your Story | Risa Simon, AAKP Ambassador |
| Table 22 | The Kidney Precision Medicine Project: Creating a Kidney Atlas | Paul Kimmell, MD, MACP |
| Table 23 | Tips for Returning to Work After a Kidney Transplant | Renee Bova-Collis, MSW, LCSW |
| Table 24 | Safety First: Infection Prevention In & Out of the Dialysis Facility | Priti Patel, MD, MPH |
| Table 25 | The Hidden P's: Managing Phosphorus and Potassium | Myles Wolf, MD |

Saturday's Lunch with the Experts Location: Lobby Level, Congressional AB

| Table 2 | Simple Diet Changes that Can Help You Slow the Progression of Kidney Disease | Patricia Centron, MD |
|----------|---------------------------------------------------------------------------------|----------------------------------------------------------------------|
| Table 3 | Understanding Your Lab Values | Stephen Fadem, MD, FASN, FACP, Chair, AAKP Medical Advisory Board |
| Table 4 | Maintaining Employment and Kidney Disease | Bruce Tippets, AAKP Ambassador |
| Table 5 | The Importance of Patient-Centered Research (Featured PCOR Track) | Janice Lea, MD, AAKP Board of Director |
| Table 6 | What To Do When You Have a Grievance with Your Dialysis Facility | Renee Bova-Collis, MSW, LCSW |
| Table 7 | Simple Ways to Stay Active with Kidney Disease | Payal Shah, AAKP Ambassador |
| Table 8 | Building Relationships with Elected Officials | Jim Myers, AAKP Board of Director, Ambassador |
| Table 9 | Financial & Insurance Resources for Kidney Patients | Kathy Trombly, MSW, LCSW |
| Table 10 | Understanding the Organ Donation Allocation Process | Stacey Punnett, RD, CCTC |
| Table 11 | Fight the Fatigue: Managing Anemia | Charlene Berry |
| Table 12 | The Importance of Managing Diabetes | Akhtar Ashfaq, MD |
| Table 13 | The Importance of Managing High Blood Pressure | Scott Cohen, MD |
| Table 14 | Understanding and Managing Gout | Brian LaMoreaux, MD |
| Table 15 | Transitioning from In-center Hemodialysis to Home Dialysis | Melissa Bensouda, AAKP Ambassador |
| Table 16 | Understanding the Food Nutrition Facts Label | Jennifer Moore, MS, RDN, CSR, LDN |
| Table 17 | Dining Out with Kidney Disease | Lana Schmidt, AAKP Board of Director, Ambassador |
| Table 18 | Managing My Medications | Rajani Ranga, Pharm D. |
| Table 19 | Being an Effective Advocate for Your Loved Ones (For Caregivers) | Sandra Kennedy, MSW, LCSW |
| Table 20 | Taking Care of Yourself While Taking Care of Your Loved One | Gloria Peninger, AAKP Ambassador |
| Table 21 | Understanding Access Options: Catheter, Graft, Fistula | Steven L. Belcher, RN, MSN, MS |
| Table 22 | Tips for Cooking Kidney-Friendly | David Rodriguez, AAKP Board of Director, Ambassador |
| Table 23 | Genetics and Kidney Disease: What You Need to Know | ТВА |
| Table 24 | Dental Health and Kidney Disease | Cheryl Thomas, RDH |

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Irish Holiday Dialysis

Kibow Biotech, Inc.

Kindness for Kidneys

Making Dialysis Safer for Patients Coalition

National Kidney Foundation

Nestle Health Science

NxStage Medical, Inc.

OPKO Renal

Osprey Medical

PKD Foundation

Quality Insights Renal Network 5

Reata Pharmaceuticals

Retrophin, Inc.

Urban Kidney Alliance

Veterans Transplantation Association

VidaFuel

Virginia Commonwealth University Transplant

AAKP Thanks the Contributions of the Following Individuals

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Robert Friedman

Edward Hickey

Norris McReynolds

Mr. & Mrs. James Miller

Glenda Roberts

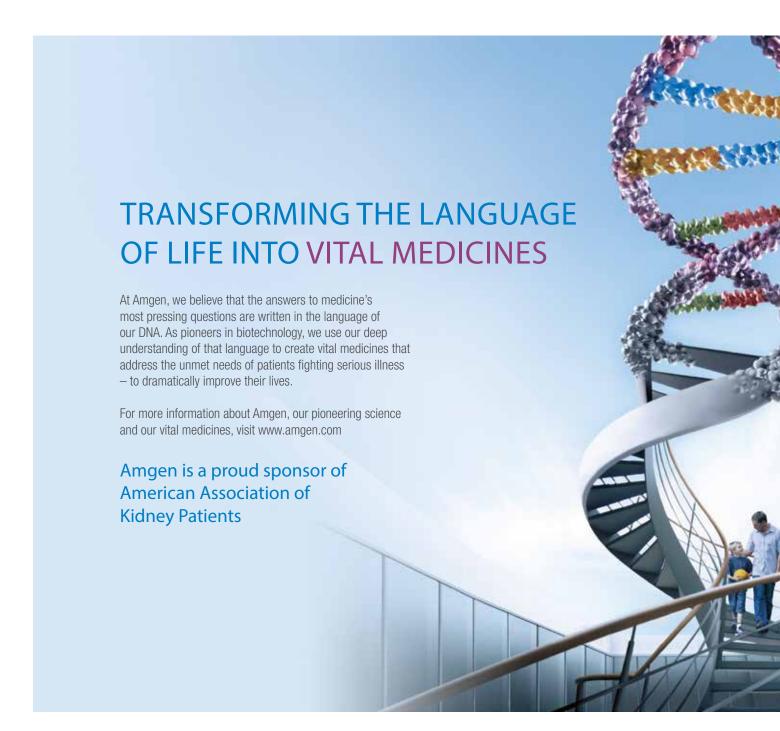
Sharron Rouse

Mary Sheppard

Nancy Uhland









More Frequent Home Hemodialysis

What Patients Report and Studies Confirm



LESS STRESS ON THE HEART

20% Fewer low blood pressure episodes¹





MORE ENERGY & VITALITY

More energy to do the things you love¹²



FEWER MEDICATIONS



MORE LIKELY TO RECEIVE A KIDNEY TRANSPLANT

14% Increased incidence of transplantation⁵



IMPROVED SEXUAL FUNCTION



ABILITY TO WORK AND GO TO SCHOOL



IMPROVED APPETITE

Eat and drink more of what you like11



IMPROVED SLEEP QUALITY

26% Reduction in restless leg syndrome8 15%-17% Reduction in sleep problems⁸



IMPROVED POST-DIALYSIS RECOVERY TIME

87% Improvement in time to recovery³ 5% Reduction in mortality for each hour that recovery time is reduced4

TALK TO A PATIENT CONSULTANT TO LEARN MORE ABOUT MORE FREQUENT HOME HEMODIALYSIS

Our consultants are all former or current patients or care partners who can walk you through what to expect when going home. Call 1-888-200-6456 to connect with our team.

Risk and Responsibility

The reported benefits of home hemodialysis (HHD) may not be experienced by all patients.

The NxStage System is a prescription device and, like all medical devices, involves some risks. The risks associated with hemodialysis treatments in any environment include, but are not limited to, high blood pressure, fluid overload, low blood pressure, heart-related issues, and vascular access complications. When vascular access is exposed to more frequent use, infection of the site, and other access related complications may also be potential risks. The medical devices used in hemodialysis therapies may add additional risks including air entering the bloodstream, and blood loss due to clotting or accidental disconnection of the blood tubing set.

Home hemodialysis with the NxStage System during waking hours may not require a care partner, provided a physician and a qualified patient agree that solo home hemodialysis is appropriate. Patients performing nocturnal treatments are required to have a care partner. Care partners are trained on proper operation and how to get medical or technical help if needed.

Certain risks associated with hemodialysis treatment are increased when performing solo HHD because no one is present to help the patient respond to health emergencies. If patients experience needles coming out, blood loss, or very low blood pressure during solo HHD, they may lose consciousness or become physically unable to correct the health emergency. Losing consciousness or otherwise becoming impaired during any health emergency while alone could result in significant injury or death. Additional ancillary devices and training are required when performing solo HHD.

Certain risks associated with hemodialysis treatment are increased when performing nocturnal therapy due to the length of treatment time and because therapy is performed while the patient and care partner are sleeping. These risks include, but are not limited to, blood access disconnects and blood loss during sleep, blood clotting due to slower blood flow and/or increased treatment time, and delayed response to alarms when waking from sleep.

Patients should consult their doctor to understand the risks and responsibilities of performing these therapies using the NxStage System.

References

- 1. The FHN Trial Group. In-center hemodialysis six times per week versus three times per week. N Engl J Med. 2010;363(24):2287-2300.
- 2. Rocco MV, Lockridge RS, Beck GJ, et al. The effects of frequent nocturnal home hemodialysis: the Frequent Hemodialysis Network Nocturnal Trial. Kidney Int. 2011;80(10):1080-1091.
- 3. Jaber BL, Lee Y, Collins AJ, et al. Effect of daily hemodialysis on depressive symptoms and post-dialysis recovery time: interim report from the FREEDOM (Following Rehabilitation, Economics and Everyday-Dialysis Outcome Measurements) Study. Am J Kidney Dis. 2010;56(3):531-539.
- 4. Rayner HC, Zepel L, Fuller DS, et al. Recovery time, quality of life, and mortality in hemodialysis patients: the Dialysis Outcomes and Practice Patterns Study (DOPPS). Am J Kidney Dis. 2014;64(1):86-94.
- 5. Weinhandl E, Liu J, Gilbertson D, Arneson T, Collins A. Transplant incidence in frequent hemodialysis and matched thrice-weekly hemodialysis patients. Poster presented at National Kidney Foundation Spring Clinical Meeting, 2012.
- 6. Kotanko P, Garg AX, Depner T, et al. Effects of frequent hemodialysis on blood pressure: Results from the randomized frequent hemodialysis network trials. Hemodial Int. 2015;19(3):386-401.
- 7. Pinciaroli, AR, Results of Daily Hemodialysis in Catanzaro:12-Year Experience With 22 Patients Treated For More Than One Year. Home Hemodial Int. 1998;(2):12–17.
- 8. Jaber, B.L., Schiller, B., Burkart, J.M. et al, Impact of short daily hemodialysis on restless legs symptoms and sleep disturbances. Clin J Am Soc Nephrol. 2011;(6):1049–1056.
- 9. U.S. Renal Data System, USRDS 2015 Annual Data Report: Table 6.3.
- 10. Data source: NxStage patient data on file.
- 11. Spanner E, Suri R, Heidenheim AP, Lindsay RM. The impact of quotidian hemodialysis on nutrition. Am J Kidney Dis. 2003;42(1 suppl):30-35.
- 12. Finkelstein FO, Schiller B, Daoui R, et al. At-home short daily hemodialysis improves the long-term health-related quality of life. Kidney Int. 2012;82(5): 561-569.
- 13. Kraus MA, Cox CG, Summitt CL, et al. Work and travel in a large Short Daily Hemodialysis (SDHD) program. Abstract presented at American Society of Nephrology Annual Conference, 2007.





While you are there take pictures with fun props and post them to your social media channels.

Let everyone know what fun you are having while learning using hashtag: #KidneyPatients19

The Social Media Center is located in the Exhibit Hall. Hours are:

Fri, Sept. 6:

7:00 am - 8:30 am & 4:30 pm - 6:30 pm

Sat, Sept. 7:

7:00 am - 9:00 am & 3:30 pm - 5:30 pm

Sun, Sept. 8:

7:30 am - 9:00 am

The Social Media Center is sponsored by:



On Social Media: @RetrophinRare

Tag Us!

Don't forget to tag AAKP when posting to social media!



@kidneypatient



@kidneypatients



@kidneypatients



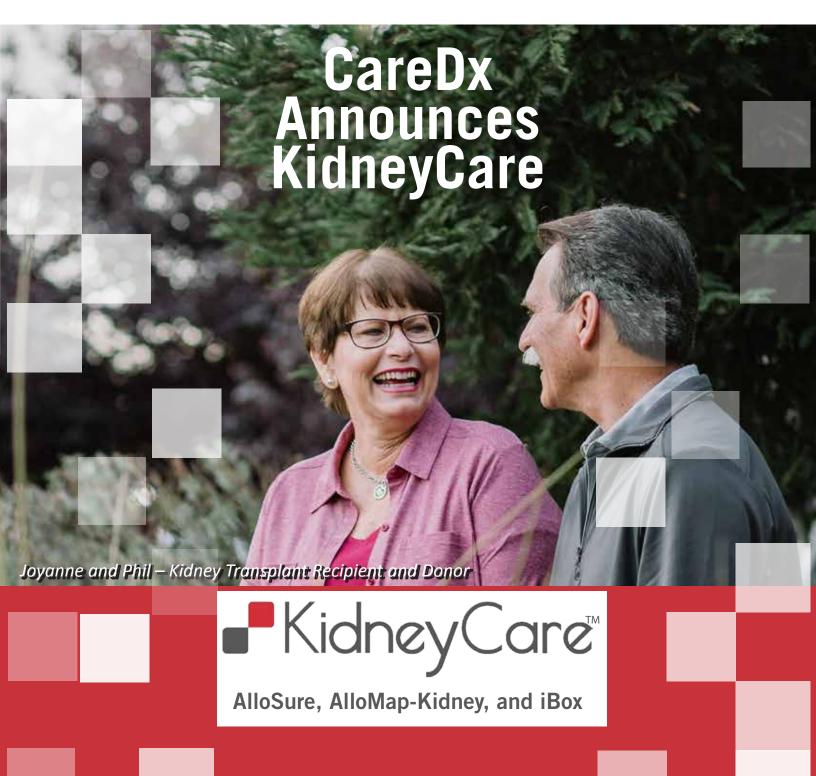


Stop by our
Wellness Center in the
Exhibit Hall to receive
Blood Pressure
and Glucose Screenings

Ask an Expert:

Educational and informational resources available on fistula and catheter care, hypertension, diabetes, nutrition





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www.AAKP.org

Give \$50 for AAKP's 50th!

Help support the AAKP and celebrate its 50-year legacy of education, advocacy and patient engagement by making a tax deductible donation today!

All funds go toward supporting the mission of AAKP and ensuring that those who suffer from kidney disease are provided with the information and resources they need to understand their condition, make informed choices about their care and achieve their aspirations. Donations will also go toward supporting the AAKP Ambassador Program and ensuring that the true patient voice is represented to policy-makers whose decisions impact patient care.

Donate today at www.AAKP.org/giveyourway

Any amount helps – together we ARE making a difference in the lives of those affected by kidney disease and those yet to be diagnosed.

Follow us on social media: Twitter: @kidneypatients Facebook: @kidneypatient





We are proud to support the American Association of Kidney Patients.



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Dialysis Clinic, Inc.

A Non-Profit Corporation

DCI is the nation's largest non-profit dialysis provider. We are a leader in quality kidney care.

DCI's mission is focused on finding innovative ways to care for and empower patients to live their best possible life.





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Do you want to use your voice to make a difference in the kidney community? Join the oldest and largest, fully independent kidney patient organization in the U.S. and become an AAKP Ambassador!

Some things Ambassadors do!

- Advise government agencies and research organizations on how to incorporate the patient voice and influence change
- Attend meetings with legislators, congressional staff & other federal officials
- Speak at local and national events, conferences & webinars
- Represent AAKP at conferences, events & exhibitions
- Author articles on various topics (aakpRENALIFE, AAKP Blog)
- Network with fellow kidney patients & caregivers

AAKP's Ambassador Initiative is part of our Center for Patient Engagement & Advocacy that works to ensure that the voices of kidney patients and their families are heard. AAKP Ambassadors are our most engaged volunteers.

They are seasoned experts on kidney disease, dialysis, transplant, and living kidney donation, and their involvement is crucial to our mission.

Join the largest kidney patient organization as an Ambassador! Contact Erin at ekahle@aakp.org to learn more.



If you have Polycystic Kidney Disease you may qualify for a clinical study

FALCON is a Phase 3 clinical study evaluating the effectiveness and safety of bardoxolone methyl (an oral investigational drug) in patients with Autosomal Dominant Polycystic Kidney Disease (ADPKD).

You may be eligible for this study if you:

- · Are 18 to 70 years of age
- · Have been diagnosed with ADPKD

Other eligibility criteria will apply.

The investigational drug, study-related procedures, and doctor visits will be provided at no cost. If you travel to the site for your study visits, travel expenses will be reimbursed, and compensation for study-related time may be provided.

For more information on FALCON, please contact:

Joanna Figueroa, RN
Patient Navigator
joanna.figueroa@reatapharma.com
(469) 442-4754



www.PKDstudy.com

This study is being sponsored by Reata Pharmaceuticals, Inc. www.clinicaltrials.gov (NCT03918447) ENG Version 1.0

WHERE OTHERS SEE COMPLEXITY, WE SEE HOPE FOR PATIENTS AND FAMILIES



At Mallinckrodt, our focus is to improve the lives of patients worldwide. Making a difference is what drives us every day as we work to develop innovative therapies and cutting-edge technologies for underserved patients with severe and critical conditions.

We see challenges as opportunities to change lives. It is our passion. It is Mallinckrodt.

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Mallinckrodt is proud to support AAKP's Annual National Patient Meeting.

Congratulations on your 50th Anniversary!





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AAKP is the oldest and largest, fully independent kidney patient organization in the U.S.A.

Join today and start enjoying the **benefits of membership** including free e-newsletters, aakpRENALIFE magazine and much more!

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At Hansa we focus on rare patients, not rare diseases.

At Hansa Biopharma, we are working to develop new treatments for people whose immune systems begin to attack healthy cells and organs in their own bodies.

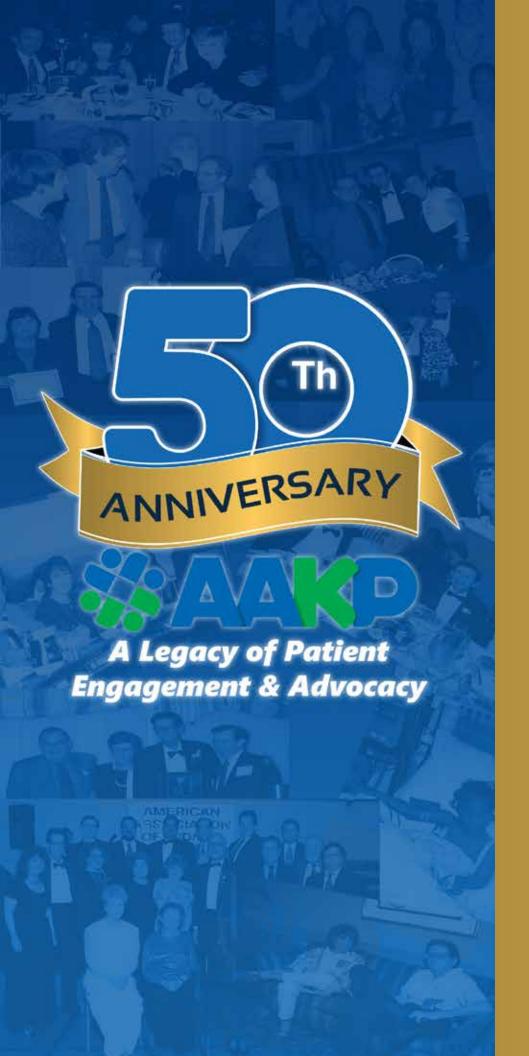
Today, we are focusing on patients with end-stage kidney disease who have donor-specific antibodies creating an immunological barrier to transplantation. Our goal is to cross this barrier, allowing for transplantation.

With our innovative research, Hansa will strive to eliminate rare immunological diseases, helping one person at a time.

And we won't stop until we do.

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Thank you to OOKP's Presidents,

Past and Current

1969 – 1970 Samuel Orenstein

1971

Louis Gibofsky

1972

Shep Glazer

1973

Shep Glazer/Wilbur Mils (Honorary President John Martin, Jr.)

1974 - 1975

Josephine Berman

1976 - 1979

Abe Holtz

1980 - 1981

Gilbert Wilix

1982 – 1983

John Newmann

1984

Josephine Berman

1985 – 1986

Paul Feinsmith

1987 - 1990

Lou Sand

1991 - 1994

A. Peter Lundin, MD

1995 - 2000

Joseph D. White

2001 - 2007

Brenda Dyson

2008 - 2010

Roberta Wager, RN, MSN

2011

Carolyn Price

2012 - 2014

Sam Peterson

2014 - 2018

Paul T. Conway

2018 – present Richard Knight



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