

KHI Patient and Family Partnership Council (PFPC) 2020 Call for Applications

The Kidney Health Initiative (KHI) is calling for applications to serve on the KHI Patient and Family Partnership Council. Patients or care partners interested in serving should review the following Call for Applications and [apply](#) by Friday, Sept 4, 2020

Background of the Kidney Health Initiative:

More than 37 million Americans have kidney disease, and more than 600,000 Americans have kidney failure, also known as end-stage kidney disease (ESKD). The Kidney Health Initiative was established in September 2012 to “catalyze innovation and the development of safe and effective patient-centered therapies for people living with kidney diseases.” As a public private partnership between the American Society of Nephrology (ASN) and the US Food and Drug Administration (FDA), KHI is the largest consortium in kidney disease with more than [100 organizations and companies](#). KHI is dedicated to improving patient safety and promoting the development of the best possible therapies for diseases that affect the kidneys and quality of life for millions of people around the globe.

KHI Patient and Family Partnership Council:

Patients and their care are at the heart of the KHI mission. To further patient involvement in KHI, the Patient and Family Partnership Council (PFPC) will partner with KHI Board of Directors and staff to advise and make recommendations on member project proposals, KHI projects and overall efforts of KHI so that the patient’s voice, experience and involvement is meaningful and effective.

KHI PFPC Role and Responsibility:

The KHI PFPC is charged with driving patient-centered innovation in every stage of the development of devices, drugs, and biologics by:

- Assisting with the development of strategic priorities and goals that can help FDA, KHI members and patients partner to drive patient-centered innovation;
- Empowering patients and care partners to have equal and fair representation in product development conversations by developing and leveraging current educational and training tools;
- Advising KHI members on project proposals and identifying patients and care partners to serve on KHI or FDA related projects and initiatives; and
- Developing patient-centered project(s) to submit for KHI endorsement.

The KHI PFPC is not a decision-making group. KHI PFPC’s ideas and recommendations will be made to the KHI Board of Directors for review and enrichment.

Composition of KHI PFPC:

KHI PFPC is comprised of up to 10 members who are patients, family members or care partners.

Rather than a seat dedicated to kidney patient organizations, the KHI PFPC will be populated based on the following ideas:

1. Focus on diversity which includes, but is not limited to, age and experience, ethnicity, and gender.
2. Consider a well-balanced representation by patient type which includes, but it not limited to the following:
 - Transplant recipient(s)
 - Dialysis patient(s)
 - Hemodialysis
 - Home Hemodialysis
 - Peritoneal Dialysis
 - CKD patient(s) – prior to kidney failure
 - Rare disease patient(s)

Term:

Members of the KHI PFPC are assigned a term of 3 years, with the option of renewing once. To help with the staggering of terms, the KHI PFPC Nominating Committee can recommend 1-3 year terms for renewing KHI PFPC members.

Estimated Time Commitment:

KHI PFPC members are asked to join conference calls that are held each month and the KHI PFPC will be asked to meet in-person twice a year – once in conjunction with the Annual KHI Stakeholders Meeting and once at ASN Kidney Week for a meeting and orientation with incoming PFPC members. Additional time commitments may include, but are not limited to, service on KHI project workgroups and KHI PFPC-initiated projects. Due to COVID-19, there are no plans for in-person meetings. ASN will continue to assess the situation to ensure safety through 2021.

Compensation:

KHI PFPC will follow the KHI reimbursement guidelines. No financial compensation or honorarium will be offered for their service on KHI PFPC.

Application and Deadline: Friday, Sept 4, 2020

All interested candidates should apply to serve on this council. The application can be sent to khi@asn-online.org with a subject line of “Application: Patient and Family Partnership Council”.

Please include the following information in your application:

1. Name and contact information
2. Resume or CV
3. KHI member that you will be representing (if applicable)
4. Reason for wanting to participate in the KHI PFPC (no more than 400 words).
5. Explanation of how you will contribute to the KHI PFPC (no more than 400 words).

6. Based on your experience as a patient or care partner (and/or the experience(s) of other patients or care partners), outline specific concerns or issues regarding the development of new products for people living with kidney disease and how you would like to see these addressed or resolved (no more than 400 words).
7. Statement that you have the time to commit to the KHI PFPC.

Managing potential or perceived conflict of interest is important to KHI (see [KHI Conflict of Interest policy](#)). All applicants will be asked to complete a disclosure form which outlines any potential conflict of interest. KHI staff will send a link to the form once the application is received.

Selection and Notification

Applicants who are selected from the preliminary screening will be asked to complete a 30-minute phone interview with the KHI PFPC Nominating Committee, to be held the week of September 21, 2020.

Those selected to serve as members of the KHI PFPC will be notified in mid-October and begin their service on January 1, 2021.

Deadline for Applications: Friday, Sept 4, 2020

Contact:

If you have any questions, please do not hesitate to contact:

David White, KHI Patient and Family Partnership Council Chair at davidmwhite@aya.yale.edu or KHI staff at khi@asn-online.org.