

KHI Patient and Family Partnership Council (PFPC) 2024 Call for Applications

The Kidney Health Initiative (KHI) is calling for applications to serve on the KHI Patient and Family Partnership Council (PFPC).

KHI is a pre-competitive public-private partnership among the American Society of Nephrology and the U.S. Food and Drug Administration (FDA). Since 2012, KHI has grown to include more than 75 member organizations such as patient advocacy and health professional organizations, industry and manufacturers, dialysis providers, government agencies, and research organizations, fostering partnerships to develop treatment options for diseases that affect the kidney.

Patients and their care givers/care partners are at the heart of the KHI mission. To further patient involvement in KHI, the PFPC partners with KHI Board of Directors and staff to advise and make recommendations on member project proposals, KHI projects and overall efforts so that the voice, experience, and involvement of people with kidney diseases are meaningful and effective.

Responsibilities:

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 federal liaisons, KHI members and patients partner to drive patient-centered innovation.
- Providing patients and care givers/care partners an equal and fair representation in product development conversations by developing and leveraging educational and training tools.
- Developing patient-centered projects.
- Advising KHI members on project proposals and identifying patients and care partners to serve on KHI projects and initiatives.

The KHI PFPC is not a decision-making group, instead, ideas and recommendations are provided to the KHI Board of Directors.

Additional responsibilities of PFPC members include:

- Attending monthly KHI PFPC videoconferences and meetings held in conjunction with KHI events.
- Serving on KHI project workgroups and PFPC-initiated projects.
- Serving as a KHI PFPC spokesperson, when appropriate.
- Supporting document review and project contributions.

The three-year member term will start on **January 1, 2025**, with the option of one, two-year renewal. No financial compensation or honorarium will be offered for service on KHI PFPC.

Application process:

Rather than a seat dedicated to kidney patient advocacy organizations, the KHI PFPC is populated with a focus on diversity and balanced representation by type of patient experience which includes, but is not limited to transplant recipients, dialysis patients (center-based hemodialysis, home hemodialysis, peritoneal dialysis), CKD (non-kidney failure) patients, rare disease patients, and care givers/care partners.

Applications must be received by Friday, August 30, 2024, by 5:00 p.m. EDT.

Interested individuals should submit an application package that includes:

- 1. Name and contact information
- 2. Resume or CV including list of relevant publications, abstracts, speaking engagements, honors or awards, or other examples of recognition within the kidney community.
- 3. Reason for wanting to participate in the KHI PFPC (no more than 400 words).
- 4. Explanation of how you will contribute to the KHI PFPC (no more than 400 words).
- 5. Based on your experience as a patient or care giver/care partner, outline specific concerns or issues regarding the development of biomedical products for people with kidney diseases and how you would like to see these addressed or resolved (no more than 400 words).
- 6. Statement that you have the time to commit to the KHI PFPC.
- 7. At least one recent (within last five years) professional reference or letter of support.

The application package and any inquiries should be sent to <u>khi@asn-online.org</u> with the subject line "Application: Patient and Family Partnership Council."

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

Applicants who are selected from the preliminary screening will be asked to complete a virtual interview. The candidates will be notified of the final decision by December 2024.