

Who funds Dialysis Patient Citizens (DPC)?

We receive support from every sector of the kidney community, as well as contributions from many individual donors, including those who have kidney disease, who are on dialysis or who have undergone transplants. Our corporate sponsors are all recognized on our website.

DPC was established in 2004 with the mission of elevating the patient voice with policy makers in order to improve dialysis patients' quality of life. Like many voluntary health associations, we received our initial funding from a corporate sponsor when we first organized and launched. In an effort to demonstrate transparency to policy makers about these donations, the original name for our organization was DaVita Patient Citizens, since our membership initially consisted of DaVita patients. However, with patients from other providers joining our group and the expansion of our funding to multiple corporate donors, our name was changed to Dialysis Patient Citizens in 2009. We remain proud of our autonomy, led by a Patient Board that determines our priorities and sets our advocacy agenda without funder influence or interference.

DPC was formed as a 501(c)(4) non-profit organization in order to avoid any restrictions on our patient-led advocacy efforts. As a 501(c)(4), we are able to focus our efforts on bringing dialysis patients to Washington, DC, to meet with their Members of Congress, organize state advocacy days, provide training to our advocates and legally advocate on their behalf. The one limitation of being a 501(c)(4) organization is that contributions to DPC are not tax deductible. Therefore, we have not focused our fundraising efforts on individual donors, who, by demographics, are limited in resources to fund a national patient advocacy organization. Despite that fact, we still have a couple thousand individuals who make personal donations to DPC on an annual basis to help us elevate the patient voice. This dedication alone speaks volumes for who we are and the value we provide for patients to actively engage in federal and state advocacy.

In 2015, DPC retained well-respected fundraising consultants Capacity Partners to help us expand our donor base and appeal. Their analysis of our database found that "a majority [of DPC Members] are retired or unemployed with a range of income levels skewing to the mid-low side." As a result, Capacity Partners recommended that DPC continue to focus on corporate giving to maximize our fundraising efforts, though we still solicit and encourage donations among our members to demonstrate a unified voice for quality care, access and choice for patients and their loved ones.

Capacity Partners found that DPC has successfully recruited some of the most vulnerable individuals in society as our members, despite their limited resources, and that we are working hard to get their personal struggles and stories before policy makers to make a difference for others facing kidney failure. We view our job as reminding healthcare decision makers that dialysis patients are real people – they are much more than just a line-item in the budget. We want individuals who rely on dialysis care to live life to the fullest.

Do corporate donations drive your advocacy priorities?

No. Our 501(c)(4), patient-led structure allows us to remain autonomous. While many patient organizations include corporate executives on their Boards for fundraising purposes, our leadership wanted to protect their independence and decided not to give corporate sponsors a voice in our decision-making process. As a result, we are governed by a volunteer Patient Board that consists entirely of individuals who have experienced kidney failure and intimately know the struggles and needs of their fellow patients. In fact, our bylaws require that our President, Vice President and a majority of our Board members are current dialysis patients. Those Board members who are not currently on dialysis, received kidney transplants and were previous dialysis patients.

Our Patient Board sets our policy priorities, informed by annual blinded membership surveys conducted by Kynetec and Ipsos international research firms. We received feedback from more than 1,000 patient members and nearly 400 caregivers/family member for our 2019 Annual Membership Survey. In addition, our Patient Board meets in person at least twice a year, including an extensive Board Retreat for strategic planning. We also hold multiple Board conference calls between in-person meetings.

Our Patient Board has always started their discussions by asking, “As patients ourselves, what’s in the best interest of our fellow dialysis patients?” That is the one and only measure that our Board members use for determining our work. Our funders are blinded and firewalled from determining our organizational priorities, policy agenda and advocacy efforts.

We are the dialysis patient voice. Our policy agenda is patient-driven and not influenced by any of our industry funding sources, though we appreciate their dedication and support to our 28,000 members. We know what our members want and need, and we fiercely advocate for those policies and programs that better the quality of care and quality of life for individuals living with kidney disease, kidney failure and kidney transplants.