DPC’s State Advocacy Program Works to Advance State Policies that Improve Dialysis Patient Outcomes
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Historically, health policy issues that impact End Stage Renal Disease (ESRD) patients have largely been focused at the federal level since the vast majority of ESRD patients are on Medicare, a federally-run health insurance program, as their primary insurer. Hence, much of the decision-making with regard to ESRD policies has come either from Congress or from within the U.S. Department of Health and Human Services (HHS) since both have oversight of the Medicare program.

However, in recent years, states have become more actively engaged in health policy legislation, in large part due to their expanded role in the development and implementation of the state health care exchanges following the passage of the Affordable Care Act as well as other political dynamics at play. Rather than continue to have a narrow scope focused primarily on state Medicaid programs and budget issues, several states have begun to introduce broader legislation and regulatory policies that would impact ESRD patients at a much larger level. As a result, DPC has shifted more attention to state policy efforts over the past few years, and in 2019 established a state advocacy program that now includes two dedicated, full-time staff who are focused on state policy issues and government relations across the country.

Although DPC’s state advocacy program is still in its infancy, its’ staff have already helped lobby legislators to defeat state legislation that threatened patient access to care and vital financial resources to help patients afford their insurance premiums. DPC staff have also made inroads educating policy makers about dialysis patients’ needs and have been working with coalition partners to help introduce and advance legislation that provide more support for ESRD patients and lead to better patient outcomes. Examples of such legislation include: expanding access to Medicare supplemental insurance, or Medigap, for ESRD patients under age 65; increasing caretaker support to assist with home dialysis so that more patients may opt for home dialysis; ensuring protections and benefits for living organ donors so as to increase the supply of kidneys available for transplant; establishing kidney disease prevention and education task forces to increase awareness, slow disease progression and help patients better navigate their treatment options; and supporting telehealth expansion that includes ESRD services so that dialysis patients have greater flexibility to ensure continued access to vital care.

The COVID-19 pandemic has crippled many state budgets, temporarily halted state legislatures’ ability to focus on a plethora of issues unrelated to COVID-19 and presented challenges to engaging face-to-face with state law makers. However, it has also presented an unexpected opportunity for DPC state advocacy staff to focus on relationship-building activities with state legislators and their staff by serving as a helpful resource of COVID-19 information specific to dialysis and transplant patients. This, in turn, has increased awareness about DPC as a valuable patient-led advocacy organization engaged in policy and education efforts on behalf of patients with kidney disease and their families. Moreover, it has also enabled us to begin to identify key legislators across the states who can be champions for dialysis patients and in helping us build a stronger base of support across the country to advance the issues important to our patient members while involving our members in the process.

So while DPC’s state advocacy program is still relatively new, it is rapidly gaining traction through its engagement efforts with state legislators and other policy stakeholders to educate them on our policy priorities that will lead to better health outcomes for dialysis patients. We look forward to our continued work with our Patient Ambassadors and Board Members to elevate the voice of ESRD patients and advance our state and federal advocacy priorities, and we encourage those of you not already engaged to reach out to us and to get more involved.

For more information regarding DPC’s policy priorities, please visit the policy section of our website: https://www.dialysispatients.org/policy-issues/.

For general ESRD information and a list of resources in your state, please visit: https://www.dpcedcenter.org/resources/state-by-state-resources/.

To join DPC or apply for our Patient Ambassador program to help elevate the voice of dialysis patients, please visit: https://www.dialysispatients.org/get-involved/.