



*Improving Life Through
Empowerment*

November 8, 2021

Joint Committee on Public Health
General Court of the Commonwealth of Massachusetts
24 Beacon Street
Boston, MA 02133

Re: Support for SB 1377 and HB 2401

Dear Chairwoman Comerford, Vice Chair Moran, Chairwoman Decker, Vice Chair Murray and Members of the Joint Committee:

My name is Vanessa Evans, a resident of Marblehead, and a member of the Dialysis Patient Citizens (DPC) Board of Directors. I am writing on behalf of DPC to offer comments in support of SB 1377, presented by Senator Chandler and HB 2401, presented by Representative Jon Santiago, to create a task force for chronic kidney disease and education.

Founded in 2004, DPC is a nationwide, non-profit, patient-led organization dedicated to improving the lives of End Stage Renal Disease (ESRD) patients by advocating for favorable public policy to support dialysis patient needs and improve patient outcomes. Our policies and mission are guided solely by our membership and our patient-led volunteer Board. DPC is committed to promoting access to high-quality dialysis care for individuals with ESRD; to the prevention of, delayed onset of, and safe transition to ESRD among individuals with chronic kidney disease (CKD); and access to kidney transplantation as well as to other alternatives to dialysis that may emerge. Currently in Massachusetts, there are 12,752ⁱ residents with End Stage Renal Disease and 3,577ⁱⁱ listed on the kidney transplant waiting list.

I have been living with kidney disease since the age of twelve, and a dialysis patient for over 24 years. In my journey dealing with kidney disease, I was fortunate to receive a kidney transplant through a living kidney donation from my mother. Unfortunately, over time the transplant failed, and I found myself back on dialysis, starting at a dialysis center and eventually transitioning to home dialysis. Living with kidney failure impacts my life each and every day. The introduction of these bills creating a task force studying CKD and key issues including the impact of CKD on minority communities, ways to increase kidney transplantation, and a state-wide campaign to educate residents about prevention to reduce incidence of kidney disease across the Commonwealth is an example of government doing excellent work on behalf of its citizens.

If enacted, this legislation would establish a task force made up of a diverse set of stakeholders – including legislators, the public health commissioner, providers, kidney patients, insurers, advocacy organizations and community organizations representing health equity interests – appointed by the Chairs of the Joint Committee on Public Health. The task force goal is broad, examining CKD,

1001 Connecticut Avenue, Suite 1230 • Washington, D.C. 20036 • Toll Free Number
1.866.877.4242 • Fax 1.888.423.5002

www.dialysispatients.org • Email: dpc@dialysispatients.org

DPC is a 501(c)(4) non-profit organization governed by dialysis patients.

November 8, 2021
DPC letter of support SB 1377/HB 2401
Page 2 of 2

transplantation, organ donation, existing disparity of disease rates within minority communities and the feasibility for an opt-out donor registry. The outcome is creation of a sustainable, cost-effective plan for prevention, early screening, diagnosis, and treatment of CKD to reduce the burden of kidney disease statewide. The task force would also develop an ongoing public information campaign designed to reach a broad audience, targeting those who are most vulnerable to developing kidney disease. Finally, the task force shall produce a report before December 31, 2023, regarding its work to the clerks of the senate and house of representatives.

Expanding education and prevention efforts could help CKD patients recognize and manage their kidney disease more effectively and also help reduce or delay kidney failure which necessitates dialysis treatment or a transplant in order to survive. Even those CKD patients who progress to ESRD, or kidney failure, would benefit from earlier detection and more education because they will be more informed and better prepared to address their disease and treatment options, which then leads to better health outcomes. Therefore, DPC and I urge you to support the creation of a CKD prevention and education task force.

DPC staff and I look forward to collaborating with legislators on this and other important policy issues that support patients with kidney disease and create more equitable health outcomes. If you have any questions or would like more information, please feel free to contact Elizabeth Lively, Eastern Region Advocacy Director at Dialysis Patient Citizens, at (312) 890-1428 or elively@dialysispatients.org.

Thank you for your consideration of this important legislation

Sincerely,

Vanessa Evans
Member, Board of Directors
Dialysis Patient Citizens

ⁱ United States Renal Data System, 2020 USRDS Annual Report

ⁱⁱ <https://optn.transplant.hrsa.gov/data/view-data-reports/state-data/#>

cc: Hrant Jamgochian, J.D., LL.M, Chief Executive Officer, Dialysis Patient Citizens
Elizabeth Lively, Eastern Region Advocacy Director, Dialysis Patient Citizens