September 5, 2018

The Honorable Mitch McConnell The Honorable Chuck E. Schumer

U.S. Senate U.S. Senate

Office of the Majority Leader Office of the Minority Leader

The Capitol, S-230 The Capitol, S-221

Washington, DC 20510 Washington, DC 20510

Dear Majority Leader McConnell and Minority Leader Schumer:

The undersigned patient advocacy organizations represent millions of Americans with serious illness, and partner with multiple stakeholder organizations to raise awareness, educate, fund biomedical research, provide patient services and work with Congress on behalf of patients. Our organizations collectively write to voice our concern with the Patient Advocacy Transparency Act. We are mindful that Congress is actively engaged in determining appropriate solutions to address the nation’s opioid crisis. However, the Patient Advocacy Transparency Act (S. 3000) would be potentially burdensome on patient advocacy organizations; especially small organizations that may not have resources available to adhere to reporting requirements included in the legislation. In addition, many patient advocacy organizations are committed to transparency and already disclose fiduciary relationships with various stakeholders.

Currently, patient advocacy organizations are not covered under the Physician Payment Sunshine Act (Sunshine Act). The existing Sunshine Act requires pharmaceutical manufacturers and medical device companies to disclose data on payments and transfers of value – travel, research gifts, speaking fees, and meals – made to physicians and teaching hospitals. This public policy was implemented to increase transparency of fiduciary relationships between companies and health care providers.

S. 3000 seeks to expand Sunshine Act reporting obligations by requiring manufacturers of opioids (i.e. drug, device, biological, or medical supply companies that make opioids) to report payments made to patient advocacy organizations engaged in advocacy on issues related to opioids. It is important to note that patient advocacy organizations do not receive reimbursements for patient care, unlike those covered recipients (physicians and teaching hospitals) under the Sunshine Act that are reimbursed through the Center for Medicare and Medicaid (CMS).

Requirements in the Patient Advocacy Transparency Act would be difficult for patient advocacy organizations to comply with; especially small organizations that may not have the same resources available to adhere to new reporting requirements. Any additional resources expended on reporting would be diverted from important mission-related activities. Patient advocacy organizations already disclose fiduciary relationships with various stakeholders when submitting annual reports to the Internal Revenue Service (IRS) via 990 tax forms. Moreover, to remain transparent, many of these organizations also disclose 990 tax forms and other documents on their websites for the public to view.

Our organizations are committed to transparency and representing the millions of patients we advocate for every day. We welcome the opportunity to work with you as you consider the broader opioid legislation, and the Patient Advocacy Transparency Act. Thank you for your consideration of our concerns.

Sincerely,

American Cancer Society Cancer Action Network

Arthritis Foundation

Cancer *Care*

Lupus Foundation of America

National Health Council

The Aids Institute