



August 30, 2017

Tim Boyd, MPH
Director of State Policy
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The Honorable Ed Hernandez
Chair, Senate Health Committee
California State Senate
State Capitol, Room 2191
Sacramento, CA 95814

Re: NORD Concerns Regarding AB 265 and its Impact on Patients

Dear Chairman Hernandez:

On behalf of the 1-in-10 California residents with one of the nearly 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) writes to express concern regarding the potential passage and enactment of AB 265 (Prohibition on Prescription Drug Price Discounts).

NORD is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. We are committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient assistance services.

After reviewing AB 265, we are concerned that several vague and sweeping provisions of this legislation will unnecessarily prohibit assistance programs such as NORD's RareCare that provide essential health services to patients in California. NORD supports the intent of this legislation to eliminate assistance programs that solely exist to drive patients to higher cost treatments. However, the vast majority of programs offered by manufacturers and independent charities provide comprehensive health services to patients that help them adhere to their care plan (including their prescribed medication) and maintain insurance coverage. If enacted as written, AB 265 could do more harm than good to California patients and ultimately lead to an increase in costs rather than a reduction.

The first concerning provision of this legislation pertains to the definitions of the types of assistance that would be prohibited if a less expensive, therapeutically equivalent drug were available. Section 1 specifies that the prohibited forms of assistance include, "*but [are] not limited to,*" the services defined therein. Such language opens the door for the prohibition of services unrelated to the dispensing of therapeutically equivalent medication.

Second, while AB 265 specifies that it shall not prohibit assistance from independent charities, its definition of such charities is far too vague. For example, the language states that charities cannot allow a manufacturer to "exert any direct or indirect *influence* or control over the charity



or subsidy program.” NORD strongly supports the intent of this provision as it could help protect truly independent charities like ours; however, we are concerned that it may be difficult for charities operating assistance programs that provide support for medication to truly sever all connections with the manufacturers. As a result, we fear that coordination with manufacturers over certain aspects of their medication could be misconstrued as influence and thus lead to the complete elimination of the program.

This is a particular challenge for rare diseases, as the number of patients prescribed a medication can be as few as a few hundred or a few dozen. In these cases, patients often have a relationship with NORD and the drug manufacturer dating back to the initial clinical trial and FDA approval.

Once again, thank you for the opportunity to comment on this legislation and express our concerns regarding its impact on patients. More information about NORD’s patient assistance programs is included at the end of this letter. If you have any questions about our comments or NORD’s programs, please feel free to contact me at tboyd@rarediseases.org. In addition, NORD’s volunteer California State Ambassadors, Vanessa Puopolo (Vanessa.puopolo@rareaction.org) and Erin Delman (Erin.delman@rareaction.org) are available to provide specific insight into how rare disease patients in California interact with patient assistance programs.

Sincerely,

A handwritten signature in black ink that reads "T Boyd".

Tim Boyd, MPH

Director of State Policy

Cc: Vanessa Puopolo, NORD California Co-Ambassador

Cc: Erin Delman, NORD California Co-Ambassador

About NORD’s Rare Care Program

Since 1987, NORD has operated patient assistance programs (PAPs) to help rare disease patients to obtain life-saving or life-sustaining medications that they could not otherwise afford. NORD’s programs (known collectively as RareCare Assistance Programs) provide eligible individuals medication assistance, as well as financial support with insurance premiums and co-pays, diagnostic testing assistance, and travel for consultation with disease specialists.



NORD'S RareCare Assistance Programs are patient-centric and designed to meet the unique aspects of the respective disorder to reduce the financial barriers to care for the rare disease community. NORD's Patient Services Representatives work closely with individuals (patients or caregivers), assessing patients' overall health care needs, their financial and insurance status and any other access concerns, offering supportive means for best-outcome-oriented, comprehensive care. NORD's representatives are highly engaged with the individuals and families whom we serve and are well-educated regarding their unique, and all too often devastating, medical needs. To find out more about RareCare, please visit rarediseases.org