

JOHN de FOREST

2534 Lake Street
San Francisco, CA 94121 #266
March 21, 2012

Secretary Diana Dooley
California Health and Human Services Agency
1600 Ninth Street – Room 460
Sacramento, CA 95814

HBEX

cc: KJ

Dear Secretary Dooley:

I now have three friends who suffer from Parkinson's disease.

As a member of the Parkinson's community, it is my understanding that California is preparing for implementation of the aspect of the Patient Protection and Affordable Care Act (ACA) that requires all covered health plans, effective 2014, to offer a comprehensive package of "essential health benefits." In December, Department of Health and Human Services (HHS) Secretary Kathleen Sebelius issued guidance regarding states' essential health benefit plans, and directing each state to select, by the third quarter of this year, a benchmark plan. HHS guidance on this matter raises serious questions and concerns for the Parkinson's community, and I ask you to ensure that California adopts an insurance framework that protects patients' access to necessary prescription drugs and good, affordable care.

Parkinson's disease is a chronic, progressive neurological disease that affects an estimated 500,000 to 1.5 million Americans. In particular, I write to bring to your attention and seek your leadership in addressing two facets of this issue that are of critical importance for individuals living with Parkinson's and other chronic conditions: accessibility to prescription drugs and cost sharing.

Accessibility to Prescription Drugs

The HHS proposal requires prescription drug formularies to cover one drug per category or class. This is entirely inadequate as it endorses a significantly lower standard than exists under federal policy (Medicare Part D requires coverage of at least two drugs per category or class). If not revised for 2014, it is likely that this will make life-changing medications unavailable to individuals like my friends whose health and quality of life depend upon them.

Parkinson's, like many other chronic diseases, affects each person differently. Each person responds uniquely to medication(s) and may experience side effects from the drugs they take. Having at the disposal of my health care providers as many options as possible in the treatment of this disease is, therefore, extremely important to my friends.

HHS proposes re-evaluating this policy two years after implementation – in 2016. This means that my friends or others with Parkinson's in California may be forced to refill a prescription for a drug that does little or nothing to address the symptoms of this cruel disease not just once, but a total of 24 times: once a month for a total of two years.

In addition, Medicare Part D includes six protected classes, including anti-depressants that are of importance to the many people with Parkinson's who frequently experience this symptom or co-morbidity. HHS should include protected classes for drugs that are more universally needed for serious conditions.

Cost Sharing

The HHS guidance states that the issue of plan cost sharing will be addressed "in the near future." This is distressing. For people like my friends, affordability of care and treatments is acutely important and can significantly affect their lives. They cannot reasonably be expected to make informed decisions about plan choice without a clear sense of the cost of co-pays and premiums. This is extremely important for people living with Parkinson's, a debilitating disease that for many has significantly lowered or completely eliminated any earning potential. For those on a fixed income, the issue of co-pays and premiums can make the difference between receiving care or not.

It is also extremely concerning that, according to HHS guidance, state plans may impose service limits. This may limit access to critically necessary services, such as physical and speech therapy, for people with Parkinson's. While details have yet to be provided, significant limits on services critical to treatment and well-being would be contrary to the statutory requirement to provide these essential benefits.

Whatever framework California adopts, the impact cost will have on quality of care and life for people with Parkinson's and other chronic diseases must be taken under careful consideration.

Conclusion

As California prepares for implementation of this piece of the ACA, I look to you to address the concerns of the Parkinson's community, specifically: the need for a standard that provides plans with the necessary flexibility to ensure patients have adequate access to necessary medication, as well as a cost-sharing framework that ensures medications are affordable. Residents of California such as my friends living with Parkinson's and other chronic diseases are depending on your leadership on these matters.

Thank you for your attention.

Sincerely,



CC: Governor Brown
Leadership of the Senate and Assembly
Department of Insurance