



May 19, 2020

Mr. Jim Donelon
Commissioner of Insurance
1702 N. Third Street
Baton Rouge, LA 70802

Re: Support for LDI Rule 40

Dear Commissioner Donelon,

On behalf of the 1-in-10 individuals in Louisiana with one of the approximately 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) writes to thank you for the strong actions you've taken to protect Louisianans grappling with both the health and economic effects of the COVID-19 crisis. However, one of these critical consumer protections expired on May 12, 2020. We urge you to act immediately and resume the protections against loss of health coverage due to inability to pay premiums, for 90 days after the end of the state's COVID-19 emergency declaration.

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 services.

People with pre-existing conditions are at increased risk of infection and adverse health outcomes from COVID-19. Maintaining access to quality health coverage in the face of job loss or other loss of income due to the economic downturn caused by this virus is critical for rare diseases patients, for not only COVID-related treatment if they receive a diagnosis, but to support their ongoing, life-saving treatment and care. This is why your decision to issue Emergency Rule 40—Moratorium on Policy Cancellations and Non-Renewals for Policyholders in Louisiana during the Outbreak of Coronavirus Disease (COVID-19) - was so helpful to vulnerable populations, including rare disease patients and families that are facing a sudden and unexpected loss of income and an inability to currently pay their premiums.

The job loss crisis is being felt most acutely in Louisiana. According to the Department of Labor Bureau of Labor Statistics, during the month of March 2020, Louisiana had the highest unemployment rate in the nation at 6.9%¹. Without a doubt, the unemployment rate for April and in the months to come will continue to get worse. Immediately bringing back the protections for an additional 90 days after the end of the COVID-19 emergency declaration will allow the crucial additional time needed for businesses to reopen, jobs and income to return, and insured Louisianans to resume making premium payments.

¹ Unemployment Rates for States, Seasonally-Adjusted – March 2020.
<https://www.bls.gov/web/laus/laumstrk.htm#laumstrk.f.p> updated April 17,2020. Accessed May 1, 2020.



Louisianans who rely on their health insurance for care of their pre-existing conditions cannot bear losing their coverage, and becoming uninsured. While the Federal government's pledge to provide coverage for COVID-related treatment may provide some comfort should they be diagnosed with COVID-19, losing their health coverage means losing access to rare disease treatment, cardiac care, and life-sustaining prescriptions and services, unrelated to the current crisis. With the financial, physical and emotional impacts of the pandemic already weighing heavily on our patients, the additional prospect of losing care for critical regimens is frightening.

The health and economic impacts of the COVID-19 pandemic will continue to be felt even by those who will not face the disease themselves. On behalf of the patients and consumers we serve, we ask that you immediately take action to protect against cancellation and non-renewal of health plans for 90 days beyond the end of the state's COVID-19 emergency declaration..

Again, we thank you for taking action to protect vulnerable patients at the outset of this crisis, and stand at the ready to work with you going forward. If you have questions, please do not hesitate to contact me at hross@rarediseases.org.

Sincerely,

Heidi Ross
Director of State Policy
National Organization for Rare Disorders

Greta Gladney
Volunteer State Ambassador
Louisiana Rare Action Network