

Rare Disease

Laura Bonnell The Bonnell Foundation: Living with
cystic fibrosis and State Ambassador for the
National Organization of Rare Disorders (NORD)



Rare Disease Advisory Council (RDAC)

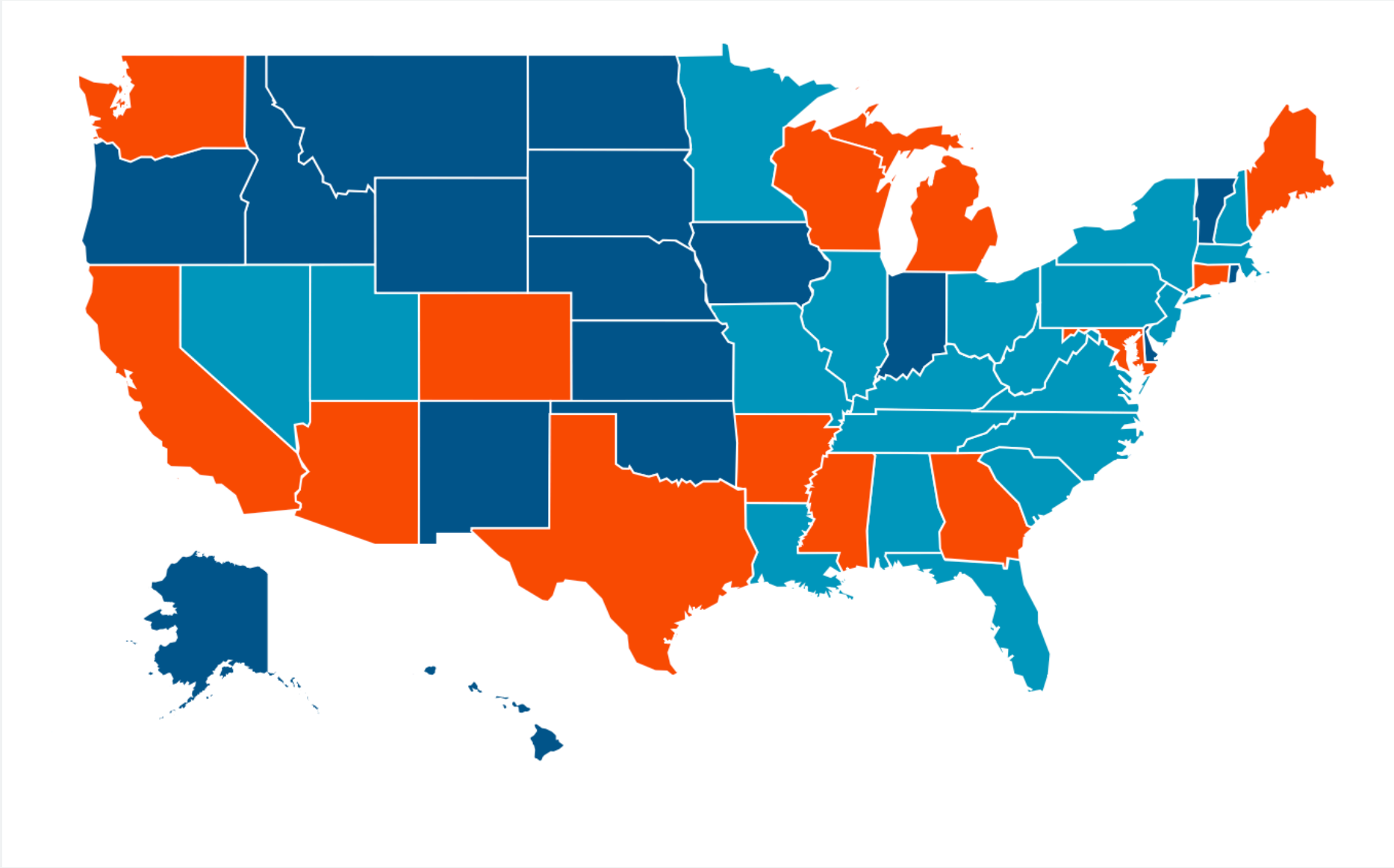
What is RDAC?

Where is it already
law?

Rare Disease in
Michigan represents 1
million people

Why is it so important? Co-pay
accumulator (out of pocket),
newborn screening, nutritional
equity, Step therapy (fail first),
QALY, Affordability Boards

The challenge:
making people
aware.



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The Bonnell Foundation: Living with Cystic Fibrosis

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