

CHRONIC KIDNEY DISEASE AND RARE DISEASE TASK FORCES



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What are task forces?

Legislators and state agencies aren't experts on every single issue, so they often rely on task forces of experts or affected citizens. These task forces submit legislative reports and policy recommendations for changes to law and advise agencies on governmental regulation and operations. Chronic kidney and rare disease task forces are typically composed of legislators, representatives from different perspectives, and stakeholders – like chronic kidney and rare disease patients. Together, they recommend prescriptive language around policy solutions to issues that impact patients.

Effective task forces include diverse representation and ensure that influential decision-makers, like elected officials, have the authority to act on the issue. They also exist within an effective administrative structure and within the appropriate state agency.

How do task forces impact people with chronic diseases?

Legislation that creates a task force is necessary to ensure all perspectives are heard and issues are given the thought and consideration they deserve. Task forces can make meaningful changes in many ways, including by:

- Working with various entities to create kidney or rare disease educational programs and increase overall awareness of kidney or rare disease in the state;
- Examining chronic kidney or rare diseases, transplantation, donation and higher disease rates in minority populations; and
- Developing a plan and campaign to raise awareness about kidney or rare diseases in the state, which can include health workshops, preventative screenings, social media and television and radio commercials.



“Through the Nevada Rare Disease Advisory Council, I find community and learn ways to better advocate for both rare and non-rare diseases...especially on public policy. Our shared goal is to feel heard and understood. RDACs highlight issues those of us face with a rare disease, but many of our concerns can apply to any disease - Christina Thielst, Member, CDC Advisory Council

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