

# Chronic Kidney and Rare Disease Task Forces



## Ensuring the Patient Voice is Heard

The Chronic Disease Coalition's top priority is to ensure patients' voices are heard whenever patient issues are being discussed. Because legislators and state agencies aren't experts on every single issue, they often rely on task forces of experts or affected citizens. These task forces submit Legislative reports and policy recommendations for changes to law, but also advise agencies on governmental regulation and operations.

## Why Task Forces Matter for Chronic Disease Patients

Legislation that creates a task force is necessary to ensure all perspectives are heard and issues are given the thought and consideration they deserve. The task force is typically composed of legislators, representatives from different perspectives, and stakeholders – like chronic disease patients themselves. Together, they recommend prescriptive language around policy solutions to issues that impact patients.

## Task Forces Implement Patient-Centered Solutions

Task forces can make meaningful changes in many ways, including by:

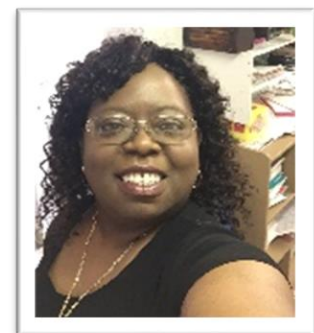
- Working with various entities to create kidney or rare disease educational programs and increase overall awareness of kidney or rare disease in the state;
- Examining chronic kidney or rare diseases, transplantation, donation, and the higher rates of affliction in minority populations; and
- Developing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

## Key Components of an Effective Task Force

An effective group will include diverse representation and ensure that influential decisionmakers, like elected officials, have the authority to act on the issue. To have its recommendations truly implemented, the task force should also exist within an effective administrative structure, and within the appropriate state agency.

We support task forces that elevate the voices of patients with chronic kidney disease and rare diseases, and strongly support work that ensure existing task forces include the patient perspective.

*"Insurance coverage is a huge issue for people who deal with chronic disease. We have to fight so hard to manage our condition and still have to battle insurers for access to health care that will keep us alive."*



**Janice Starling, Chronic Disease Coalition Ambassador, Florida**

## Interested in learning more?

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