

Crohn's & Colitis Foundation of America
Health Care Coverage & Access
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The Crohn's & Colitis Foundation of America (CCFA) advocates on behalf of the 1.6 million Americans who are affected by Crohn's disease and ulcerative colitis, which are collectively known as inflammatory bowel diseases (IBD). CCFA is also the professional member and support organization for physicians, nurses, scientists and other healthcare providers that care for patients with IBD. CCFA believes that treatment decisions should be shared between the healthcare provider and the patient.

IBD are painful, medically incurable, debilitating illnesses that affect the digestive system. Treatment is aimed at controlling the ongoing inflammation in the intestine—the cause of IBD symptoms, and can include biologics and surgery. The course of the disease varies greatly among patients and it is critical for maintaining optimal health outcomes that patients have timely access to the appropriate medications as determined by the patient and the physician. Therefore, any policy changes affecting patient access to care should protect the physician and patient decision-making relationship, ensure that patients have access to the medications and services they need in a timely manner, and ensure that patients can work with specialists as needed including IBD specialists and dieticians.

CCFA prioritizes the following as Congress considers national health care coverage policies:

- **Ensure stability by accompanying any repeal of the ACA with a viable replacement.** For patients with IBD, any interruption in coverage can result in worsened health outcomes and dire consequences like surgery to remove all or part of the bowel. Ensure that patients maintain stability in their coverage by accompanying any repeal effort with a replacement that meets the needs of patients.
- **Maintain basic patient protections and prohibit insurer discrimination against chronic disease patients.** A recent survey of IBD patients found that prior to the implementation of ACA, 88.9% of respondents said it was difficult to afford coverage, 55.3% were turned down by an insurance company, and 51.8% were charged a higher rate because of their pre-existing condition¹. It is critical for chronic disease patients that national policies sustain basic patient rights enacted in the ACA:
 - Prohibit discrimination against patients with pre-existing conditions
 - Allow young adults to stay on their parent's insurance until age 26
 - Limit patient out of pocket spending
 - Prohibit lifetime annual caps
- **Improve the quality of insurance plans.** Patients with chronic diseases need to be able to access a range of treatments, services, and specialists in a timely manner in order to optimize their health outcomes. In the IBD patient survey, 81% of patients found it difficult to obtain insurance with adequate coverage prior to the implementation of ACA. After the implementation of the ACA, patients frequently reported being subject to step therapy and other medical management protocols that unduly limited access and resulted in worse health outcomes. National health

¹ Rubin, DT, Feld LD, Goepfinger SR, et al. The Crohn's and Colitis Foundation of America Survey of Inflammatory Bowel Disease Patient Health Care Access. *Inflammatory Bowel Diseases*. 2016

policies must require minimum coverage standards, guard against discrimination, and ensure that patients can access the care they need within the time they need.

- Prohibit discrimination against chronic disease patients manifested in insurer formularies and coverage determinations
 - Require standards for minimum benefits to ensure patients have access to a range of services
 - Require standards for network adequacy to ensure patients can see the physicians and specialists they need
 - Protect shared decision-making between patients and providers by requiring insurers to provide timely communications on medical management protocols as well as transparent and expedient appeals processes
- **Ensure the affordability of insurance plans and that patients share in cost-savings.** Provide low income patients with premium and cost-sharing assistance as well as access to programs like Medicaid. Limit patient cost-sharing for medications in specialty tiers.

CCFA *opposes* the following components of recently proposed ACA alternatives:

- **CCFA opposes any allowance for insurers to charge patients more for preexisting conditions, including requiring continuous coverage.** Any allowance of discrimination against preexisting conditions would severely limit the ability patients with IBD to access affordable health insurance and needed care for their condition. The proposal to require patients to maintain continuous coverage in order to avoid higher costs for their preexisting condition is discriminatory against patients with IBD who are especially vulnerable to lapses in coverage. Several factors can lead to a lapse in coverage that are not the fault of the patient including clerical error, changes in employment, and efforts by insurers to move sick patients off their plans. The continuous coverage requirement is overly punitive and disproportionately affects patients with chronic diseases.
- **CCFA opposes shifting patients to high risk pools or any other mechanism that segregates chronic disease patients from healthy patients.** Separate is never equal and setting aside chronic disease patients places them at high risk for lesser coverage. In addition state-based high risk pools as well as the ACA Preexisting Conditions Insurance Program (PCIP) held standards for inclusion that likely missed several patients in the individual market with preexisting conditions that did not meet the risk pool eligibility requirements.

For additional information, please contact Sarah Buchanan, CCFA's Director of Advocacy, at sbuchanan@ccfa.org.