Background: The total health care expense for a family is tied both to the overall premiums (monthly amounts paid for health care coverage) as well as the out of pocket expenses (e.g., payments that individuals make for accessing their health insurance coverage). Out of pocket expenses include:

- **deductibles** -- amount you pay for health care services before your health insurance begins to pay),
- **copayments** -- a fixed amount you pay for a health care service, usually when you receive the service and which can vary by the type of service (e.g., pharmacy, physician office visit), and
- **co-insurance** -- your share of the costs of a health care service, usually figured as a percentage of the amount the insurer allows to be charged for services and required after you meet your deductible.¹

Primary immunodeficiency diseases (PI) are a group of more than 250 rare, chronic disorders in which part of the body’s immune system is missing or functions improperly. For many of these patients, it is necessary to receive life-saving immunoglobulin replacement therapy regularly for the rest of their lives, as well as have access to specialty physicians to help manage their disease. Given this critical focus for PI patients, the Immune Deficiency Foundation (IDF) has been actively following the implementation of the Affordable Care Act (ACA) and how it may affect those with PI. There are three critical elements – (1) cost of overall premiums, (2) out of pocket costs (especially as it relates to specialty pharmaceuticals), and (3) access to specialists.

**Premiums and the “Cadillac tax” cause shift to OOP.** Under the ACA, employers could be subject to a 40 percent tax on the amounts by which the costs of their sponsored plans exceed government-set thresholds. Cost of coverage includes the total contributions paid by both the employer and employees, but not cost-sharing amounts such as deductibles, coinsurance and copays when care is received. For planning purposes, the thresholds for high-cost plans are currently $10,200 for individual coverage, and $27,500 for family coverage.² Those thresholds are very close to the average costs of premiums in 2014, which were annual premiums of $6,025 for single coverage and $16,834 for family coverage.³ Thus, to reduce the cost of coverage to avoid the Cadillac tax, health plans are shifting more costs to the patients through out of pocket costs (discussed in detail below).

**More and more cost sharing.** In addition to paying specific premiums for insurance coverage, individuals are also responsible for their specified cost sharing. The ACA sets maximum out-of-pocket (OOP) spending limits, but otherwise does not specify the combination of deductibles, copayments, and coinsurance that plans must use to meet the actuarial value requirements (more about actuarial value below). For example, one insurer may choose to have a relatively

¹http://www.bcbsm.com/index/health-insurance-help/faqs/topics/how-health-insurance-works/deductibles-coinsurance-copays.html
²http://www.cigna.com/aboutcigna/informed-on-reform/cadillac-tax
high deductible but low copayments for office visits and other services, while another may choose a lower deductible but higher copayments or coinsurance for each service. In general, the out-of-pocket maximum may be no more than $6,600 for an individual and $13,200 for two or more people in 2015.4

Focus on specialty pharmacy. Given the relative flexibility in designing the benefit structure, one key focus of cost containment has been specialty pharmacy. These drugs, typically used to treat chronic, serious, or life-threatening conditions, such as cancer, rheumatoid arthritis, growth hormone deficiency, primary immunodeficiencies, and multiple sclerosis, are often priced much higher than traditional drugs.5 Expenses for specialty pharmaceuticals, which can cost up to $10,000 for a month of treatment, are on the radar. Traditional pharmacy spending is expected to grow 3.9 percent in 2016, but specialty pharmaceuticals by 22.3 percent, says the National Business Group on Health, citing a report by Express Scripts, a pharmaceutical benefits management firm.6

Key concerns with specialty pharmacy. To help reduce the overall expenditures for specialty pharmaceuticals, health plans have instituted three key management strategies – (1) substantial cost sharing for specialty drugs; (2) required diagnostic testing as a condition of coverage; and (3) managing the site of service. All of these cost saving policies can have a direct and detrimental impact on those needing the key medications.7 Thus, while the overall goal of the ACA was to provide basic health care coverage for everyone, those with severe chronic conditions may be left out in the cold.

Access to specialty physicians. Another way to control the overall costs of premiums is to have a narrow network of providers. Narrow-network plans have grown in popularity, particularly on the ACA’s insurance exchanges, because their cheaper premiums appeal to price-sensitive consumers. About 70% of plans sold on the exchanges in 2014 featured a limited network, and their premiums were up to 17% cheaper than plans with broader networks, according to a study by consulting firm McKinsey & Co.8 Given the rise in narrow network plans and the small number of specialty physicians included in such plans,9 it may be difficult for individuals with PI to receive appropriate care from a specialty physician when needed.

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5http://www.healthaffairs.org/healthpolicybriefs/brief.php?brief_id=103
7http://www.healthaffairs.org/healthpolicybriefs/brief.php?brief_id=103
8http://www.modernhealthcare.com/article/20150328/MAGAZINE/303289988