

BROAD INSURANCE REFORMS

(apply to employer sponsored insurance as well as Exchange plans):

- **Keep ban on annual and lifetime limits.**
 - Many individuals with hemophilia will routinely use \$250,000 to \$1 million worth of clotting factor each year, for life, depending on the severity of their individual conditions. An adult with hemophilia could hit a \$1 million cap in just two or three years; an individual experiencing inhibitors or other complications could reach that cap even faster. The ACA's ban on annual and lifetime limits is thus a critical protection for bleeding disorders patients against losing their insurance due to such caps.
- **Keep coverage for children up to 26 years old.**
 - As an expensive and chronic disease, hemophilia comes with a high, life-long price tag. Members of the hemophilia community routinely hit the catastrophic out-of-pocket maximums on their health insurance plans. Bearing these catastrophic costs (on top of the premium costs to purchase insurance in the first place) is extremely difficult for almost anyone – but is almost impossible for many young people early in their work lives. Staying on their parents' insurance until age 26 allows young people with bleeding disorders time to become established in their careers before they have to shoulder the weighty burden of paying the year-in, year-out costs of their healthcare.
- **Guaranteed issue, renewability, no discrimination on basis of pre-existing conditions, no rating restrictions for pre-existing conditions.**
 - Bleeding disorders are genetic conditions that are present at birth. Disallowing insurance companies to discriminate on the basis of a pre-existing condition has made it possible for patients living with a bleeding disorder to buy the insurance necessary to properly manage their disorders. Not allowing insurance companies to increase premiums based on patients' health condition has ensured access to health insurance for those who most need it.
- **Meaningful coverage/appropriate scope of health benefits (cover prescription drugs, HTC).**
 - Insurance is not meaningful unless people can afford it and unless it covers the services and products people need in order to stay healthy. Prior to enactment of the ACA, some individuals with bleeding disorders only had access to insurance plans that excluded coverage for the medications and/or services necessary to control or prevent joint- and life-threatening bleeding episodes. This kind of under-insurance is functionally equivalent to a complete lack of insurance. Standards for what health plans must cover (prescription drugs, chronic disease management, etc.) are critical in order for insurance to be meaningful. Also, limits on out-of-pocket spending must extend to a wide range of services in order to be considered meaningful.
- **PCORI/CMMI.**
 - Keep value based innovation systems that include evidence based policy decisions and incorporate the patient voice.

- **Oppose High Risk Pools.**

- The bleeding disorders community, unfortunately, has long experience with high risk pools and their many shortcomings. High risk pools were used in 35 states prior to the enactment of the ACA to cover people with pre-existing conditions. These pools generally offered limited coverage, with high deductibles and low annual and lifetime coverage caps. Premiums could be prohibitively expensive (often 200% or more of the prevailing rate in the individual market) and many states were unable to make up the resulting shortfall in funding when premiums and deductibles didn't cover costs of care for the high-need enrollees. Because so many high risk pools were chronically underfunded, they implemented enrollment caps and waiting lists that excluded many (sometimes most) of the individuals who applied for coverage. Thirty-three states imposed annual and/or lifetime caps on pool participants; individuals with bleeding disorders who reached their cap were often forced onto state Medicaid. Some pools also implemented tight restrictions on the scope of coverage - including pre-existing condition exclusions, the very problem they were designed to remedy.

- **Maximum Out of Pocket Costs.**

- As more and more insurance plans shift costs to consumers, it is incredibly important that patients are protected against unlimited out-of-pocket costs. Hemophilia and other bleeding disorders require costly medications in order to maintain health, and shifting costs to patients can lead to utilization management, nonadherence and poor health outcomes. It is vital that our patients not only have access to the products and services they need, but that they are able to afford them as well.

MEDICARE:

- **Continue progress toward closing Part D prescription drug donut hole.**

- While clotting factor is covered under Part B of Medicare, not Part D, many Medicare-eligible individuals with hemophilia also live with co-morbidities (including HIV and HCV) that require prescription drug therapies covered under Medicare Part D. Products used to treat von Willebrand disease are also covered under the Part D benefit. Continued progress toward closing the Part D donut hole is essential for this population, which already bears high and continuing costs for the treatment of their bleeding disorders.

MEDICAID AND CHIP:

- **Keep Medicaid expansion for low income adults, maintain federal Medicaid funding, and reauthorize CHIP.**

- Bleeding disorders are treatable and individuals can lead healthy and productive lives despite the disorder, but treatment comes at an extremely high cost. Low income individuals and families coping with hemophilia are at great risk if they lack employer-sponsored health insurance and cannot afford policies in the non-group market. Medicaid and CHIP provide an absolutely critical safety net for this segment of the bleeding disorders population. Block grants for Medicaid have the potential to lead to a significant decrease in state Medicaid budgets and leave states responsible for costs arising from demographic and other changes. It is vital that the federal government maintains its commitment to states so they are able to serve vulnerable populations.