Dear Director Angoff:

The American Plasma Users Coalition (A-PLUS) and the National Organization for Rare Disorders (NORD) are pleased to submit comments on the Interim Final Rule for Pre-Existing Condition Insurance Plan Program under the Patient Protection and Affordable Care Act (“Affordable Care Act”) which was published in the Federal Register (Vol.75, No. 146) on July 30, 2010.

A-PLUS is a coalition of national patient organizations created to address the unique needs of over 125,000 patients with rare diseases that use life-saving plasma protein therapies. NORD was founded in 1983 to advocate for the enactment of the Orphan Drug Act, and remains the leading advocate for over 30 million patients with an estimated 7000 known rare diseases.

We are pleased to offer our suggestions and comments on the following provisions in the rules:

Pre-Existing Condition Insurance Plan Program (PCIP)

A-PLUS and NORD strongly support the creation of the Pre-Existing Condition Insurance Plan Program through the Affordable Care Act. These temporary plans will provide new coverage options needed for many individuals who have been denied access to health insurance because of a pre-existing condition. However, our organizations are ultimately concerned that the patients we serve will not be able to access these plans due to limited funding and eligibility barriers, therefore negating the intent of the Affordable Care Act.

Funding Limitations and Third Party Payer Prohibitions

While A-PLUS and NORD are conscious that there are program funding limitations, we are working to ensure that the patients and families we represent, who are uninsured or underinsured, have access to coverage through the PCIP program. Charitable organizations fill gaps in the existing health care infrastructure by providing health insurance premium assistance to many patients with rare conditions who would not be able to otherwise afford the cost. A majority of the current state high risk pool structures, in order to reduce costs and limit coverage, place prohibitions on these charitable organizations from subsidizing the premiums. If state PCIP programs are allowed to adopt similar bans on charitable organizations subsidizing the premium, this will limit participation in the programs. Limiting participation is counter to the intent of Congress in this legislation, which our organizations supported.
We believe that permitting independent non-profit organizations to provide premium assistance for these policies will ensure that uninsured individuals with low and moderate incomes face fewer barriers to enrollment in a health insurance policy through the PCIP program. Guidance should be issued to clarify to role non-profit organizations can have in providing assistance to PCIP beneficiaries.

**Eligibility and Enrollment**

A-PLUS and NORD support the provisions stated in the interim rule regarding the eligibility and enrollment policies for the PCIP program. To be eligible for the PCIP program pool a patient must have been uninsured for 6 months; a US citizen or national; and show proof of a pre-existing condition. However, while we understand that the 6-month period is defined by statute, the final rule should recognize and address the hardship a waiting period would place on people with high-cost chronic conditions.

- We support the consistent use of the definition of a pre-existing condition and its application throughout the programs developed and initiated by the Affordable Care Act.
- A-PLUS and NORD would like to also commend the Department for not requiring patients who move to another state to re-satisfy the 6-month uninsured requirement to qualify for coverage. This provision will allow patients to have greater continuity of care which will keep medical costs lower and reduce dependency on safety net programs such as Medicaid.

**Child-Only Policies**

Recently, health insurance providers have decided to cancel “child-only” policies because of the removal of the pre-existing condition discrimination provision for children 19 years old or younger in the Affordable Care Act. Because of those decisions, our organizations recommend that the Department issue guidance that will allow infants and children to access the PCIP program in their respective states.

**Definition of "other criteria" for PCIP Eligibility**

In states where the HIPAA federal fallback coverage is a Guaranteed Issue policy, Open Enrollment policy, or other form of coverage that is not a high risk health insurance pool, a patient cannot be denied coverage for a pre-existing condition but they may be subject to a waiting period. Although they cannot be turned down for coverage, many patients still cannot access a plan because of the prohibitively high cost of the premium. These same patients can therefore not produce the required denial of coverage letter for a pre-existing condition to qualify for their state’s PCIP Plan. We recommend that the Department of Health and Human Services not allow PCIP program plans to disqualify patients who otherwise comply with the eligibility requirements but could not access coverage because of a prohibitive premium. Our organizations recommend that the Department allow the cost of premiums in states without high risk insurance pools to be included in the definition of “other criteria” for eligibility to the PCIP program.

**Enrollment and Disenrollment Process**

A-PLUS and NORD support the PCIP program disenrollment policies specifically laid out under this rule. These policies include the loss of coverage if the enrollee moves out of state; obtains other creditable health insurance coverage; the termination of the PCIP itself; or any type of intentional fraud or misrepresentation.
Program Capacity Limits

Our organizations recommend that the Department of Health and Human Services publish on the Office of Consumer Information and Insurance Oversight (OCIIO) website the status of capacity limits in each PCIP program pool, even if that pool is administered by the Department. This will inform consumers of their enrollment options for the PCIP program in their respective state.

Thank you for the opportunity to submit these comments and recommendations. A-PLUS and NORD will continue to work with the Office of Consumer Information and Insurance Oversight (OCIIO) on the implementation of the Affordable Care Act to ensure that patients with rare and chronic disorders have access to the health insurance coverage they need.

For additional information, please contact Diane Edquist Dorman, NORD Vice President for Public Policy (ddorman@rarediseases.org) or Kisa Carter, HFA Public Policy Director (k.carter@hemophiliafed.org).

Sincerely,

American Plasma Users Coalition
National Organization for Rare Disorders

1 American Plasma Users Coalition (A-PLUS) membership includes: Alpha-1 Association, Alpha-1 Foundation, Committee of Ten Thousand, GBS/CIDP Foundation International, Hemophilia Federation of America, Immune Deficiency Foundation, Jeffrey Modell Foundation, National Hemophilia Foundation, Patient Services Incorporated, Platelet Disorder Support Association