



ASSOCIATION *of* PEDIATRIC  
HEMATOLOGY/ONCOLOGY NURSES

May 19, 2015

The Honorable Fred Upton, Chairman  
Energy and Commerce Committee  
U.S. House of Representatives  
Washington, DC 20515

The Honorable Diana DeGette  
U.S. House of Representatives  
Washington, DC 20515

Dear Chairman Upton and Representative DeGette:

On behalf of the Association of Pediatric Hematology/Oncology Nurses (APHON)- representing more than 3,300 pediatric hematology/oncology nurses in the United States, Canada, and around the world- we are pleased to provide our support for the 21<sup>st</sup> Century Cures Act and offer additional comments on the legislation. APHON is the professional organization for pediatric hematology/oncology nurses and other pediatric hematology/oncology healthcare professionals and is dedicated to promoting optimal nursing care for children, adolescents, and young adults with cancer and blood disorders, and their families. APHON provides the leadership and expertise to pediatric hematology/oncology nurses by defining and promoting the highest standards of practice and care to the pediatric, adolescent, and young adult communities.

### **Discovery**

APHON commends the Committee on the strong emphasis placed on research within the National Institute of Health (NIH) and naming rare and pediatric diseases and conditions a priority under the Mission Priority Focus Area. Pediatric hematology/oncology nursing is a dynamic and evolving discipline that is based on knowledge derived from theory, research and practice. It is not only the knowledge that the pediatric nurse acquires but the application of this knowledge and the ability to artfully apply it to the care of a child, adolescent and/or young adult (AYA). She/he can work in the hospital setting (inpatient unit and outpatient clinic), physician's office, home health care, radiation center, hospice/ palliative care service, and perform skills and services such as assessment of physical and psychosocial needs, administration of chemotherapy, biotherapy, immunosuppressants, teaching, supporting the patient going through their treatment by performing such interventions as administration medications to alleviate nausea/vomiting and pain, helping a child/AYA with loss of hair (body image), administering blood/blood products to alleviate anemia or thrombocytopenia, or supporting a patient through hospice/palliative care.

As the rates of pediatric and adolescent cancer increase, pediatric hematology/oncology nurses are at the forefront of care for patients and families. We respectfully request that the legislation specify that a member of the Biomedical Research Working Group as well as the Council For 21<sup>st</sup> Century Cures include a pediatric hematology/oncology nurse.

## **Development**

The inclusion of patients when considering the benefits and risks of new drugs is integral, but as the primary healthcare professional spending the most time with the patient/families, we feel that pediatric hematology/oncology nurses should also be included in the discussion. Pediatric hematology/oncology nurses are the individuals that are actually administering the chemotherapy, ensuring compliance for safe handling of drugs, and providing patient/family education for at-home chemotherapy administration. This input from the nursing perspective is integral when discussing risks and benefits of new drugs.

APHON is very supportive of the provision to reauthorize the Rare Pediatric Disease Priority Review Voucher Program. This program is extremely valuable because in 20 years the FDA has initially approved only two drugs for any childhood cancer and 1/2 of all chemotherapies used for children's cancers are over 25 years old. There are also dramatic funding disparities between adult and childhood cancer drug development. Pharmaceutical companies allocate 60% of research and development funds for adult cancer drugs and close to zero for childhood cancers. The merits of the Voucher Program can be seen from the sale of the first voucher in July 2014 for \$67.5 million which gained attention from other companies now interested in investing in pediatric drug development.

We also want to offer our support for section 2082 and 2083, Expanded Access Policy, which would make it easier for patients to get experimental drugs on a "compassionate use" basis. The lack of approved drugs for childhood cancer paired with the susceptibility of drug shortages in pediatric oncology has created a reliance on investigational drugs. For more than 50 years, cooperative clinical trials have advanced outcomes in pediatric cancer and nearly two-thirds of children have enrolled in a trial during their treatment. As drug shortages are likely to continue and approval of new cancer drugs for pediatric patients continues to occur after the development and approval for treating adult cancers, the ability to access investigational drugs will be integral.

## **Conclusion**

APHON very much appreciates your leadership in taking a comprehensive look at what steps can be taken to accelerate the pace of cures in America. We are available to work with you, your colleagues, and other stakeholders to develop and implement legislation that advances the discovery and development of disease treatments. If you have any questions, please contact me ([jami.gattuso@stjude.org](mailto:jami.gattuso@stjude.org) or 901-595-3256). We thank you for your consideration of our concerns, recommendations, and requests.

Respectfully submitted,



Jami S. Gattuso MSN, RN, CPON  
President