

#### **About ASPHO**

The American Society of Pediatric Hematology/Oncology (ASPHO) represents more than 2,000 members dedicated to setting, advocating for, and achieving the highest standards of care for children, adolescents and young adults with cancer or blood disorders and their families.

### **Health Policy & Advocacy Agenda**

ASPHO is committed to advocating and achieving one voice for pediatric hematology/oncology (PHO). The Society works in partnership with appropriate organizations to advance its advocacy priorities including:

- Ensure adequate federal funding for research, surveillance and other legislation
- Improve access to drugs, devices and biologics for children and adolescents
- Promote adequate payment for care of children by subspecialists in PHO to support needed access and workforce

## **Overview of PHO**

- **Pediatric hematologists/oncologists** provide essential care for children with blood disorders and cancer. They are medical doctors who have had at least 4 years of medical school, 3 years of pediatrics residency training, and 3 additional years of fellowship training in PHO.
- **Hematology** refers to blood disorders including sickle cell disease (SCD), anemia, and inherited and acquired bleeding and thrombotic disorders.
- **Oncology** refers to both solid tumors and blood cancers, including leukemia, lymphoma, brain tumors, bone cancers, kidney tumors, and other solid organ tumors.
- These disorders are often chronic or lifelong and require continuing collaboration to treat them.

#### **Progress in PHO**

- Pediatric-specific research on cancer and blood disorders is crucial. Children are not just small adults, and they require different treatment. Thirty years ago, few children with cancer survived, but now almost 80% of children/adolescents diagnosed with cancer are surviving more than 5 years; the majority are cured. There are over 420,000 childhood cancer survivors in the US.
- With improved treatment and supportive care, death in childhood from SCD is now rare.
  Screening programs and blood transfusion therapy have also effectively prevented stroke in children with SCD.
- Advances in hematopoietic stem cell transplantation have made this life-saving treatment available to more children. Stem cell transplantation and gene therapy are potential cures for SCD and other blood diseases.

# **Challenges in PHO**

- Although cancer survival rates are improving, there are still significant socioeconomic and racial disparities, due to a combination of unequal access to healthcare, and environmental and genetic factors. Also, very few therapies are developed exclusively for children.
- Despite substantial advances in treating SCD, not all children have access to the same level of high-quality care. SCD has not received the necessary level of funding for innovative research to cure SCD. Too few PHO providers are available for children who need them, making it difficult for families to access needed care, particularly in underserved areas.