Chair’s Update
Zora R. Rogers, MD, FAAP

Fall Greetings! I hope you all celebrated September’s dual awareness campaigns for Sickle Cell Disease and Childhood Cancer. We are all too aware of these disorders, and the challenges they bring for the families affected. The national midterm elections will be held on Tuesday, November 6. All 435 seats in the U.S. House of Representatives and 35 of the 100 seats in the U.S. Senate will be contested. In addition, 36 governors, more than 6,000 state legislators, and many other state and local officials across the country will be elected. The American Academy of Pediatrics’ Get Out the Vote campaign, #VoteKids, encourages pediatricians and others who care for children to vote with kids in mind this election. The campaign website, aap.org/votekids, includes information on what’s at stake for children and what you can do to speak up for children at the ballot box. The AAP’s #VoteKids Toolkit, which is also available on the website, includes sample social media messages, polling time infographics, an RX to Vote for patients and parents and op-ed guidelines. We all care for kids, so please BE SURE TO VOTE!

In the Section our elections were far less contentious. This month Dr. Amber Yates from Baylor College of Medicine in Houston will start her three-year term on the Executive Committee. Her election means that Dr. Gary Crouch from Uniformed Services University of the Health Sciences has completed his second term. Thank you, Gary, for all of your wise counsel and section involvement, particularly as liaison to the Council on Pediatric Subspecialties.

Since I was elected to the Executive Committee 8 years ago, SOHO has worked to provide advice to the academy to facilitate leadership on issues important to our practices, our patients, and us. Our advocacy mission remains robust and SOHO led the AAP’s decision to sign on to a letter from ASH regarding S.2465, the bill authorizing a sickle cell disease surveillance program and development about a treatment demonstration program. In addition, the AAP submitted a section requested letter supporting FDA 2018-D-1540 concerning the inclusion of Adolescent Patients on Adult Oncology Trials. This is in addition to the ongoing opportunity to work to develop meaningful CPT codes and payor advocacy positions that impact patients and pediatricians.

Also in this newsletter are articles about the Digital Transformation Initiative for the AAP website, which will enhance your ability to utilize the tools housed there. This is a work in progress for the AAP as they seek to create member value, specifically for the subspecialist. There are two sites that will include information about SOHO. The
first is a site that includes information about SOHO and how to join. The second site will require use of your AAP login and password and will be available only to SOHO members. The SOHO Subcommittees on Communications and Education will be working on ways to optimize the information available there. Over the next few months I encourage you to log on to the AAP’s website and see what you can find. Information to be found there includes more details about federal advocacy efforts, CME, and materials for patient/family education about general pediatric issues. Over the next few years, the quantity and type of information available should blossom, and we will continue to encourage our members to check it out.

In September, I had the opportunity to attend a face to face meeting of the Sickle Cell Disease Coalition (SCC) facilitated by the American Society of Hematology. This group developed as an extension of the 2015 ASH sickle cell summit, and has approached the most critical issues in sickle cell care into committees of action. AAP-SOHO is a founding member of the coalition and on the Steering Committee. The SCDC meeting brought together all of the stakeholders in SCD: patients, providers (hematologists, blood bankers, emergency physicians), federal agencies, sickle cell community organizations and pharma. The global health committee has produced brief videos focused on sickle cell disease awareness as a treatable condition. Their message may well resonate with US patients as well; and you can check them out at http://www.scdcoalition.org/priorities/global.html. The American College of Emergency Physicians has spearheaded a summit on improving emergency care in SCD and the Emergency Department Sickle Cell Care Collaborative (EDSC3) is moving along. ASH is also developing a Sickle Cell Research Implementation Registry to characterize a panel of sickle cell disease patients who are ready to be involved in specific research projects; and they have a series of guideline documents in development, several that have been shared with SOHO members as an opportunity to provide individual physician feedback. You can access the public comment page here. On the federal level the NIH: NHLBI has an active Cure Sickle Cell initiative through focused research support. The meeting’s keynote speaker, Assistant Secretary of Health Admiral Brett Giroir MD, has made improving sickle cell disease a focus of his public health efforts. Further, in his capacity as Senior Advisor for Opioid Policy he has heard our concerns that the war on opioids not prevent their availability for management of children with conditions that require them (such as sickle cell disease and cancer). The SCDC is the first national effort to get all stakeholders to talk with each other, and I am hopeful it will lead to improvements in care going forward.

As always, I welcome your thoughts and suggestions to make SOHO more responsive to your ideas and needs.

Zora R. Rogers, MD, FAAP
Chairperson,
Section on Hematology/Oncology

The Section on Hematology/Oncology Executive Committee

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Statements and opinions expressed in this publication are those of the authors and not necessarily those of the American Academy of Pediatrics or the AAP Section on Hematology/Oncology.
Greetings! An important component of the mission of SOHO is the education of physicians in training as it pertains to pediatric hematology/oncology-related topics. In keeping with our mission, we have taken two steps. First, the article below highlights important aspects of pursuing a career in pediatric hematology/oncology that we hope will be of interest to medical student and resident members of SOHO. Enjoy!

Second, to aid us in future educational planning and how to best serve trainees, we would appreciate your responses to a brief survey. It should take less than 5 minutes of your time and will be completely confidential unless you agree to share your contact information with us for further follow-up. You may access the survey at: https://www.surveymonkey.com/r/QJ2G3HL. Thanks in advance for your participation!

1. **What is pediatric hematology/oncology?**
   - Pediatric hematology/oncology (PHO) is a pediatric subspecialty dedicated to the diagnosis and management of children and adolescents with cancer and blood disorders. Pediatric hematologists/oncologists take care of diverse patient populations to include those affected by sickle cell disease and other hemoglobinopathies, anemia of all etiologies, bleeding and clotting disorders, leukemias, solid tumors and brain tumors just to name a few. There is never a dull moment as no two patients are alike, even with similar pathologies. A unique feature of this specialty is the capability to participate in the care of patients across all specialties from those with marrow suppression as a result of a viral illness to those with abnormal bleeding after a surgical procedure. It is an exciting field that is thought provoking and challenging, yet extremely rewarding.

2. **Who can be a pediatric hematologist/oncologist?**
   - You can! If you desire continuity of care and building relationships with patients and their families and have a passion for providing and coordinating care of complex patients then this is may be the field for you. If you love problem solving and welcome the challenge of caring for high acuity patients, again this could be the specialty for you. It is of utmost importance to possess effective communication skills and be a great team player, as optimal patient care in PHO requires a multidisciplinary team approach.

3. **What is pediatric hematology/oncology fellowship like?**
   - Currently, there are 70 ACGME accredited PHO fellowship programs in the United States. The fellowship training is 3 years long and traditionally begins after completion of a 3-year general pediatric residency. There are options for candidates who have earned a PhD to pursue a “fast track” course of training that requires 2 years of general pediatric residency and 4 years of hematology/oncology fellowship. In general, the 1st year is focused on developing skills in the clinical management of patients (inpatient and outpatient), with the subsequent 2 years dedicated to research, which may be laboratory or clinically based, depending upon the program. The actual breakdown and timing may vary slightly by program. In addition, there is time allotted to explore electives based upon your interests. All fellows are required to complete a scholarly product at the end of their training, which is required for board certification.

During PHO fellowship, you will learn to diagnose and treat numerous hematologic and oncologic disorders that manifest in children. This knowledge and skillset will be acquired through hands-on direct patient encounters as well as through regular series of lectures focused on PHO board content specifications. Fellows are also required to maintain a continuity clinic throughout training. Furthermore, you will become competent in performing bone marrow aspirate/biopsy and lumbar puncture procedures. As with all fellowship training, taking call is a requirement. The precise call schedule depends upon each program's infrastructure as well as the number of fellows.

4. **What lies ahead after completing pediatric hematology/oncology fellowship?**
   - Upon completing PHO fellowship training, you are eligible to take your subspecialty board exams in pediatric medicine.
hematology/oncology and to enter the workforce. The possibilities are endless. Most go on to practice in an academic setting, partaking in teaching, research, etc., but there are private practice opportunities as well.

Depending upon your interests, you may elect to subspecialize more with an additional year of training. Some examples of advanced fellowships include bone marrow transplantation, palliative care, specific components of oncology (leukemias, solid tumors, neuro-oncology, survivorship), or hematology (sickle cell, hemophilia and thrombosis).

5. **When do I start preparing to apply for pediatric hematology/oncology fellowship? What makes a strong application?**

   - Preparation should begin as soon as you decide you want to pursue a career in PHO. During residency, it is recommended to take additional rotations/electives (in addition to the standard residency requirements) to get a more thorough and diverse perspective of the field. As of this year, PHO has a new interview and recruitment cycle! Applications are now due in the fall of each year. You will apply during your final year of pediatric residency and match through the National Resident Matching Program (NRMP) approximately 6 months prior to beginning fellowship in July of the following year. See the new recruitment cycle timeline here.

   Regarding the application process, most programs require a personal statement along with (3) letters of recommendation. Your letters should be from faculty that know you well and can speak highly of your work ethic. Be prepared to justify any red flags in your application such as gaps in training, or failed STEP exams. For larger, more competitive programs, it is advantageous to have research experience and publications, preferably pertaining to some aspect of PHO supporting your passion for the field.

   For a list of PHO fellowship programs in the United States, including more detailed information on each program's requirements, click here.

6. **How can I learn more about careers in pediatric hematology/oncology?**

   - To learn more about pediatric hematology/oncology, it is always beneficial to seek out current PHO fellows and faculty that are willing to share personal experiences and provide mentorship/guidance.

   In addition, you may visit either of the following websites: American Society of Pediatric Hematology/Oncology (ASPHO) or the American Academy of Pediatrics' Section on Hematology/Oncology (SOHO).

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**Therapeutic Apheresis in Children: An Update for the Pediatric Hematology-Oncology Practitioner**

Sarita Joshi MD, MBBS, FAAP1; Tina Ipe MD, MPH2; Rasheed Abiodun Balogun MD, FACP, FASN, HP(ASCP)3; Nicole Dodge Zantek MD, PhD4; Suzanne Thibodeux MD, PhD5; (from the American Society for Apheresis “ASFA” Communications Committee).

Pediatric Hematology- Oncology practitioners are becoming increasingly involved in the planning and prescription of therapeutic apheresis (TA) procedures such as therapeutic plasma exchange (TPE), red blood cell exchange (RBC exchange), extracorporeal photopheresis (ECP), hematopoietic progenitor cell collections (HPC-A) and rarely, other cytapheresis procedures. Patients with hemologic disorders such as sickle cell disease with an acute stroke undergoing RBC exchange, high-risk malignancies such as metastatic neuroblastoma requiring progenitor cell harvests for autologous use1, or those with thrombotic thrombocytopenic purpura needing urgent TPE are just a few of the procedures that require involvement by Pediatric Hematologists and/or Oncologists2. In addition, guidance and consultation for children undergoing TA for complex multisystem disorders that may not be primarily hematologic or malignant in origin, also calls for an appreciation of the technical considerations of apheresis by the consultant and an understanding of how procedures might impact the patient's pathophysiology, anticoagulation and medication pharmacokinetics.
In children and adolescents undergoing TA, pre-determined and objective therapeutic goals are usually safely achievable regardless of the size of the patient, if adequate vascular access can be established and attention is paid to co-morbidities, concurrent medications, extracorporeal volumes, replacement fluid choices and anticoagulation prior to the procedure. These procedures, whether urgent or routine, must be customized to the size of young patients since the apheresis machines and the operating software are generally designed for use in adults. It is prudent to use an RBC or albumin prime for the circuit, if the extracorporeal blood volume at any point during the procedure is calculated to exceed 10-15% of a child's total blood volume. In a retrospective study of 186 children who had undergone a total of 1632 apheresis procedures, the most frequent complications, both per procedure and per patient, were hypotension, hypotension requiring fluid bolus, symptomatic hypocalcemia, allergic reactions, catheter-related thrombosis, catheter-related infection, and severe anemia. The true incidence in children and young adults is largely unknown and is an area of active investigation by the Pediatrics Subcommittee of the American Society for Apheresis (ASFA), an organization whose mission is to advance apheresis medicine through education, evidence-based practice, research, and advocacy.

In 2016, ASFA published the 7th edition of its practice guidelines for TA. These can be accessed at: https://onlinelibrary.wiley.com/doi/abs/10.1002/jca.21470. They have been revised every three years since 2007 (prior editions were published in 1986, 1993 and 2000) and have introduced, removed, upgraded or downgraded indications for TA based on quality and currency of evidence, thus influencing practice change. Current guidelines contain concise, disease-specific fact-sheets with recommendations for TA, based on the strength and quality of available evidence and a rigorous review of relevant literature that a practitioner may find useful when considering a patient for apheresis.

In 2018, the ASFA Choosing Wisely working-group published five recommendations to encourage dialogue between patients and physicians contemplating an apheresis procedure (http://www.choosingwisely.org/societies/american-society-for-apheresis). These urge that the rationale for a procedure is supported by evidence, that harm is mitigated against, that the procedure is truly necessary and not duplicative of other interventions or tests.

Current Hematology-Oncology-specific indications for TA, derived from the 2016 ASFA guidelines, are listed below and provide a framework for consideration by subspecialists involved in TA procedures. The body of literature supporting best practices for use of apheresis procedures in children and adolescents with hematological disorders or cancer is notable for a paucity of well-designed studies with adequate sample size that could allow for evidence-based inferences regarding benefit. Most pediatric apheresis applications and protocols are derived from adult patient studies, many of which are retrospective or observational in design, leading to a preponderance of category III indications. These issues and others underscore the need for further multicenter collaborations that could inform improvements in the care of children undergoing apheresis procedures.

For detailed information regarding technical aspects of TA, the practitioner may refer to references listed.
Therapeutic Apheresis in Children: An Update for the Pediatric...  Continued from Page 5

Hematology Oncology Disorders considered for Therapeutic Apheresis (modified from the ASFA 2016 guidelines)

<table>
<thead>
<tr>
<th>Type of Therapeutic apheresis (TA) procedure</th>
<th>RBCx: Red Blood Cell Exchange (quality of supportive evidence)</th>
<th>TPE: Therapeutic Plasma Exchange (quality of supportive evidence)</th>
<th>ECP: Extracorporeal Photopheresis (quality of supportive evidence)</th>
<th>Cytapheresis (erythrocytapheresis, thrombocytapheresis or leukocytapheresis) (quality of supportive evidence)</th>
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<tbody>
<tr>
<td>ASFA Category I: TA is standard and acceptable (primary therapy or a valuable first-line adjunct therapy), but not mandatory in all cases. (This designation is based on well-designed randomized controlled trials or on a broad and noncontroversial base of published experience.)</td>
<td>Sickle Cell disease: Acute stroke (1C) Sickle cell Disease: Non-Acute; Stroke prophylaxis/iron overload prevention (1A)</td>
<td>Thrombotic thrombocytopenic purpura (1A) Thrombotic microangiopathy, drug associated - Ticlopidine (2B) Thrombotic microangiopathy, complement mediated - Factor H autoantibodies (2C) Hyperviscosity in monoclonal gammopathies: - Symptomatic (1B) - Prophylaxis for rituximab (1C)</td>
<td>Erythrodermic Cutaneous T cell Lymphoma; Sezary Syndrome/Mycosis Fungoides (1B)</td>
<td>Hereditary hemochromatosis - Erythrocytapheresis (IB) Polycythemia Vera: Erythrocytapheresis (1B)</td>
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<td>ASFA Category II: TA is generally accepted but considered to be supportive or adjunctive to other, more definitive treatments, rather than a primary first-line therapy. (Randomized controlled studies are available for some of these disorders, but in others the literature contains only small series or informative case studies.)</td>
<td>Sickle cell disease: Acute chest syndrome (1C) Babesiosis(2C)</td>
<td>Severe Cold Agglutinin Disease (2C) Severe refractory Cryoglobulinemia (2A) Refractory ITP Immuunoadsorption (2C) Hematopoietic stem cell transplantation, (ABO Incompatible) - Major HPC, Marrow (1B) - Major HPC, Apheresis (2B) Catastrophic antiphospholipid syndrome (2C)</td>
<td>Graft-versus-host disease - Skin (chronic) (IB) - Non-skin (chronic) (1B) - Skin (acute) (1C) - Non-skin(acute) (1C) CTCL: Non Erythrodermic (2C)</td>
<td>Hyperleukocytosis: symptomatic: Leukocytapheresis-symptomatic (1B)</td>
</tr>
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Table Continued on Page 7
### ASFA Category III: Suggestion of benefit for which existing evidence is insufficient either to establish the efficacy or to clarify the risk/benefit ratio of TA. Controlled trials have produced conflicting results or those for which anecdotal reports are too few or too variable to support an adequate consensus. TA may reasonably be used in such patients when conventional therapies do not produce an adequate response or as part of an Institutional Review Board-approved research protocol.

<table>
<thead>
<tr>
<th>Disorder</th>
<th>ASFA Category III</th>
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<tr>
<td>Aplastic Anemia (2C)</td>
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<tr>
<td>Pure Red Cell Aplasia (2C)</td>
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<td>Paraneoplastic neurological syndromes TPE (2C), IA (2C)</td>
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<tr>
<td>Post transfusion purpura (2C)</td>
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<tr>
<td>Red cell alloimmunization in pregnancy: Prior to IUT availability (2C)</td>
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<td>Severe Warm AIHA (2C)</td>
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<tr>
<td>Erythropoietic Protoporphyria with liver disease</td>
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<tr>
<td>Immune thrombocytopenia- refractory(2C)</td>
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<tr>
<td>Thrombotic microangiopathy, Shiga toxin mediated</td>
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<tr>
<td>-severe neurological symptoms (2C)</td>
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<tr>
<td>-Strep pneumoniae (2C)</td>
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<tr>
<td>Thrombotic microangiopathy, hematopoietic stem cell transplantation associated (2C)</td>
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<tr>
<td>Thrombotic microangiopathy, drug associated</td>
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<tr>
<td>-Clopidogrel (2B)</td>
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<td>-Calcineurin inhibitors (2C)</td>
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<tr>
<td>Thrombotic microangiopathy, complement mediated</td>
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<td>-Complement factor gene mutations III (2C)</td>
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<td>-MCP mutations (1C)</td>
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<tr>
<td>Thrombotic microangiopathy, coagulation mediated</td>
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<tr>
<td>-THBD mutation (2C)</td>
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<tr>
<td>Henoch-Schonlein purpura</td>
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<tr>
<td>-Crescentic TPE (2C)</td>
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<td>-Severe Extrarenal disease (2C)</td>
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<tr>
<td>Heparin induced thrombocytopenia &amp; thrombosis- pre-cardiopulmonary bypass (2C)</td>
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<td>Hemophagocytic lymphohistiocytosis; Hemophagocytic syndrome; Macrophage activating syndrome (2C)</td>
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<td>Hematopoietic stem cell transplantation, HLA desensitization (2C)</td>
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<td>Erythropoietic porphyria, liver disease (2C)</td>
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<tr>
<td>Coagulation factor inhibitors: Autoantibody (2C)</td>
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### ASFA Category IV: Disorders for which controlled trials have not shown benefit or anecdotal reports have been discouraging. TA for these disorders is discouraged and should be carried out only in the context of an Institutional Review Board-approved research protocol.

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<tr>
<td>Hyperleukocytosis: Prophylactic or secondary leukocyctapheresis (2C)</td>
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<tr>
<td>Secondary erythrocytosis: erythracytapheresis, (1C)</td>
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<tr>
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Continued on Page 8
References/suggested reading:
8. [http://www.choosingwisely.org/societies/american-society-for-apheresis/](http://www.choosingwisely.org/societies/american-society-for-apheresis/)

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### Category III Chimeric Antigen Receptor T Cell (CAR-T) Therapy CPT Codes

The CAR-T Category III CPT proposal was presented* during the May 2018 AMA CPT Editorial Panel meeting. AAP CPT Advisors have the opportunity to review all the CPT proposals and comment on them. The CPT advisors requested clinical expertise of the Section on Hematology/Oncology, as well as the American Society of Pediatric Hematology/Oncology, to review this particular proposal and determine if this was something the AAP should support or not. It was determined that the AAP would support this proposal, which was ultimately approved at the May 2018 CPT meeting as new Category III CPT codes.

Category III CPT codes are temporary codes for emerging technology, services, and procedures. Category III codes allow data collection and frequency tracking for these services and procedures. If a Category III code is available and is specific to the performed service, this code must be reported instead of a Category I unlisted code. The use of Cat III codes allow physicians and other qualified health care professionals, insurers, researchers, and health policy experts to identify emerging technology, services, procedures, and service paradigms for clinical efficacy, utilization, and outcomes.

CPT Category III codes are not referred to the AMA-Specialty RVS Update Committee (RUC) for valuation and RVU recommendation because no relative value units (RVUs) are assigned to these codes. Payment for these services or

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procedures is based on payer-specific coverage policies, and many commercial payers include Category III codes in their payment schedules. Physicians who anticipate performing Category III services should work with their major payers in support of payment. Medicare typically will not include Category III codes in its annual fee schedule, and most Medicaid programs do not cover Category III services. Since conversion to Category I status provides the desired benefit not only of RVU recommendation, but also broader coverage among payers (especially government payers), an expectation exists that the initial groups* who supported Category III code development will eventually come back to the CPT Editorial Panel to request conversion to Category I status. This conversion process typically occurs during the first 5 years of Category III code use, after which the Category III code may sunset.

The CPT Editorial Panel approved the following:

1. Add a new Category III subsection titled “Cellular and Gene Therapy”
2. Add four new Category III codes (05X1T, 05X2T, 05X3T, 05X4T) with guidelines to identify chimeric antigen receptor T-Cell therapy services.
   - 05X1T Chimeric antigen receptor T-cell (CAR-T) therapy; harvesting of blood-derived T lymphocyte for development of genetically modified autologous CAR-T cells, per day
   - 05X2T preparation of blood-derived T lymphocytes for transportation (e.g., cryopreservation, storage)
   - 05X3T receipt and preparation of CAR-T cells for administration
   - 05X4T CAR-T cell administration, autologous

*The presenting societies at the May Editorial Panel meeting were:
- American Society of Blood and Marrow Transplantation
- American Society of Clinical Oncology
- American Society of Hematology
- College of American Pathologists

For additional information and questions please contact tsalsus@aap.org.

CoPS August 2018 Update

Dr. Gary Crouch serves as the AAP Section on Hematology/Oncology Liaison to the Council on Pediatric Subspecialties (CoPS). You can view the August 2018 CoPS update and additional information about CoPS on their website

AAP Payer Advocacy
For Pediatric Subspecialties

What is the AAP Payer Advocacy?

Due to Medicaid expansion and the growth of Medicaid managed care, in May 2018, the AAP Board approved expanding the scope of the former Private Payer Advocacy Advisory Committee (PPAAC) to include public payers and rename the committee as the Payer Advocacy Advisory Committee (PAAC). With more than 50% of children covered by Medicaid managed care, the AAP saw the need for advocacy to the Medicaid managed care organizations as well as to the Tricare Regional managed care contractors. PAAC is charged with examining the effect of payment and health plan medical

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policy and operations in the public and private market on pediatrics and pediatricians, as well as identify strategies to enhance access through improved health care coverage for children and pediatric services. PAAC advises the AAP and its leadership on strategies, including specific goals and action steps, to improve pediatrician's economic and organizational position in the public and private payer arena.

Through the PAAC and AAP payer advocacy staff, assistance and resources are available to help members and chapters in addressing payer issues.

The AAP meets with the largest national health plan carriers to advocate for its members and to educate payers on the importance of benefits coverage for children and appropriate payments to pediatricians. Also, the Academy has sent letters to carriers addressing several pediatric issues including clarifying Academy's policy on recommended pediatric services and advocate for payment for vital pediatric services.

Recent Payer Advocacy Achievements
AAP payer advocacy has worked with Anthem, UnitedHealthcare (UHC) and the Blue Cross Blue Shield Association (BCBSA) to facilitate pediatrician input to their medical policies. These policies are shared with the relevant AAP committees, councils and sections for pediatrician and specialty pediatrician input. The SOHO has participated in these reviews and on a few occasions, as recommended by SOHO and in collaboration with the American Society of Pediatric Hematology/Oncology (ASPHO), the AAP has sent formal letters providing clarifications and/or objecting to the carrier's policy. Recent examples of SOHO- led advocacy include:

• Anthem policy on the use of Tisagenlecleucel (Kymriah). The carrier agreed to add clarifications to the Notes of this policy that treatment that Kymriah is only appropriate at designated treatment centers.
• Advance Radiologic Imaging and Retro-review of MRI and CT in the Emergency Department stimulated discussions with Anthem that are currently in process.
• Anthem policy on Antihemophilic Factors and Clotting Factors (comments to this policy are presently under review by Anthem).

Payer advocacy articles are frequently provided for AAP News and the following may be of interest to SOHO members:

• AAP reaches out to health carriers to discuss coverage, payment [http://www.aappublications.org/news/2018/04/04/ppaac040418](http://www.aappublications.org/news/2018/04/04/ppaac040418)
• Subspecialists benefit from AAP private payer advocacy [http://www.aappublications.org/news/2017/02/01/PPAAC020117](http://www.aappublications.org/news/2017/02/01/PPAAC020117)

At the chapter level, several AAP Chapters have developed pediatric councils which meet regularly with payers in their state or region. Chapter pediatric councils serve as forums to discuss with payers their policies and administrative procedures that impact pediatrics and pediatricians. Pediatric councils have been instrumental in facilitating better working relationships between pediatricians and health insurance plans and to improve quality of care for children. AAP members are encouraged to work with their chapter pediatric council on issues with local or regional payers.

PPA Tools and Resources
AAP private payer advocacy also develops resources and tools to strengthen member's negotiation and contracting skills with payers. Resources are available on the AAP Practice Transformation site, including the Getting Paid section at [https://www.aap.org/en-us/professional-resources/practice-transformation/getting-paid/Pages/default.aspx](https://www.aap.org/en-us/professional-resources/practice-transformation/getting-paid/Pages/default.aspx) with links to:

• Resources on coding
• AAP letters to carriers and appeal letter templates which can be accessed by AAP members to use in their discussions [Continued on Page 11]
AAP Payer Advocacy For Pediatric Subspecialties  Continued from Page 10

with payers.
• Updates on alternative payment models and value-based payment

We welcome suggestions regarding other resources that SOHO members feel would benefit AAP members.

How Can You Make a Difference?
1. AAP members can assist payer advocacy by reporting payer issues through the AAP Hassle Factor Form. This resource is available on the AAP Member Center for members to report problems with payers. This information will help the AAP and chapter pediatric councils in identifying and prioritizing issues to address with carriers. To access the hassle factor form, go to https://www.aap.org/en-us/professional-resources/practice-transformation/getting-paid/Pages/Hassle-Factor-Form-Concerns-with-Payers.aspx

2. In addition, draft payer policy is shared with Section members through periodic SOHO e-updates. Section members are encouraged to review the policy and submit their feedback to the carrier as individual physicians. Based on the policy and issues identified, the Section Executive Committee may recommend that feedback /comments be submitted as an organizational response from the Academy.

3. Join your AAP Chapter and become involved in the Pediatric Council.

For additional information on AAP payer advocacy, contact Lou Terranova, Senior Health Policy Analyst at lterranova@aap.org

Call for Nominations – SOHO Payer Advocacy Contact

Background:
The mission of the Section on Hematology/Oncology (SOHO) is to educate the pediatric practice community and families regarding pediatric hematology/oncology conditions, make recommendations about health care needs of these patients, and advocate for those who provide and require the care.

The SOHO Payer Advocacy (PA) Contact positions (one to address hematology and one to address oncology-related issues) were established to support PA activities and issues related to care for pediatric PHO patients and payment of PHO pediatricians.

Liaison Responsibilities:

The responsibilities of a payer advocate would be:
1. Interface as necessary with AAP Payer Advocacy Advisory Committee (PAAC) and payer advocacy as the SOHO contact regarding payer issues. This may include occasional conference calls.
2. Convey to PAAC any payer issues identified by SOHO and its members
3. Educate SOHO members regarding existing payer advocacy resources (i.e., the hassle factor form to report payer issues and the Practice Transformation site).
4. Explore additional resources that may assist SOHO members in future payer issues (i.e., develop new and/or request current letters used by SOHO members regarding specific types of payer issues).
5. Educate SOHO members regarding current PAAC activities by sharing the PAAC Scorecard through articles in the SOHO newsletter and e-updates.
6. Explore ways to educate SOHO members about how to approach issues with private payers regarding pre-authorization and other coverage issues related to care of PHO patients (i.e., key talking points, engaging their state AAP chapter, when/how to escalate an issue to a higher level).

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Call for Nominations – SOHO Payer Advocacy Contact  Continued from Page 11

7. Facilitate review of carrier coverage and payment policies as they relate to hematology and oncology

Ideally, candidates would have an understanding of health insurance including managed care, payer contracting, in addition to coding. Ability to both see the ‘big picture’ in child health financing as well as be detail-oriented and have a balanced approach when dealing with potentially contentious issues involving payment.

Eligibility:
• Member of the American Academy of Pediatrics
• Member of the Section on Hematology/Oncology

Term: 3 years; renewable subject to Executive Committee approval

Appointment Criteria for Consideration by Executive Committee:
• Letter/email of Interest from the SOHO Member
• Curriculum vitae

Status: Members appointed by the SOHO Executive Committee

If you are interested in submitting your nomination to be considered for either the hematology or oncology position, please send the above information to skirkwood@aap.org by Tuesday, November 20th.

Hot Papers in Pediatric Hematology/Oncology


Led by investigators from Dana Farber, multiple institutions performed whole exome sequencing with specific testing for low-frequency and recurrent mutations, somatic copy number alterations, and structural variants associated with Diffuse Large B cell lymphoma (DLBCL) in 304 newly diagnosed subjects. The majority (85%) were treated with R-CHOP and followed to determine outcome-based genetic groupings. They identified the following five DLBCL clusters (C): C1) previously unrecognized favorable risk (60-70% PFS) DLBCLs of extrafollicular/marginal zone origin exhibiting structural variants of BCL6 and NOTCH2 mutations, perhaps treatable with protein kinase C beta or B cell receptor signaling agents; C2) a poor risk (30-40% PFS) activated B cell (ABC)/germal center B-cell (GCB)-independent group with biallelic inactivation of TP53, CDKN2A loss, and related genomic instability; C3) poor risk GCB DLBCLs with BCL2 variants and PTEN mutations; C4) a favorable risk (60-70% PFS) GCB DLBCL group with BCL2 translocations and EZH2 mutations, that also possess alterations in mTOR/PI3K and JAK/STAT which could be targeted with mutation specific inhibitors; C5) poor risk (30%PFS) ABC DLBCLs with MYD88 and CD79B mutations perhaps treatable with B-cell receptor signaling targeted agents. This DLBCL study confirms research published by multiple collaborators working with the National Cancer Institute that discovered similar genetic alterations categorizing ABC and GCB subtypes and potentially providing targets for DLBCL treatment. (see Schmitz R, et al. Genetics and Pathogenesis of Diffuse Large B-cell Lymphoma. NEJM. 2018; 378; 1396-1407. Doi: 10.1056/NEJMoa1801445.)


A group of international investigators obtained an integrative analysis of genetic alterations in a pediatric, adolescent and young adult cohort involving 961 tumors with 24 distinct molecular types of cancer to determine characteristics of predisposing germline variants and potential therapeutic targets. Compared to mutations previously reported in

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adult cancers, they identified different mutation frequencies in a total of 149 cancer-driver genes associated with either small mutations or structural/copy-number variants. Structural variants, hyperdiploidy, and chromothripsis (thousands of clustered chromosomal rearrangements in a single event, confined to a region in one or few chromosomes) were linked to TP53 mutation status and mutational signatures. They found that 7–8% of the children carried an unambiguous predisposing germline variant. Inherited predisposition was found most commonly in adrenocortical carcinomas (50%) and hypodiploid B-ALL (28%), followed by high-grade gliomas, ATRTs, SHH medulloblastoma, and retinoblastoma. Almost 50% of pediatric cancers had a potentially treatable identifiable target with current available therapy.


A panel comprised of individuals from the Hematopoietic Stem Cell Transplantation (HSCT) Subgroup of the Pediatric Acute Lung Injury and Sepsis Investigators (PALISI) Network, the CAR T Cell Therapy-Associated Toxicity (CARTOX) Program at The University of Texas MD Anderson Cancer Center, and several other institutions have developed consensus guidelines for the current indications of and adverse effects management of chimeric antigen receptor T-cell (CAR-T) therapy in pediatric patients.

Reviewed by: Taizo Nakano, MD, FAAP, Assistant Professor, Pediatrics, Center for Cancer and Blood Disorders Children's Hospital Colorado, University of Colorado School of Medicine.


In late 2017, the FDA approved l-glutamine oral powder to reduce frequency of pain crises and hospitalizations in adult and pediatric sickle cell patients greater than 5 years of age. Approval was based on data from this manuscript that represents a monumental collaborative effort to carry out a phase 3, multicenter, randomized, placebo-controlled, double-blinded trial testing the efficacy of pharmaceutical grade l-glutamine. The group enrolled 230 patients with sickle cell anemia or sickle β-thalassemia with a history of two or more painful crises within the previous 12 months. Study subjects were randomized in a 2:1 ratio to receive l-glutamine (0.3 g per kilogram of body weight per dose, administered twice daily by mouth) or placebo for 48 weeks. The subjects receiving l-glutamine demonstrated significantly fewer pain crises and fewer hospitalizations. Given these results, l-glutamine (Endari) was designated an orphan drug in both the U.S. and in Europe, and placed on fast track development by the FDA.


For every VTE treated, the hematologist must attempt to evaluate and predict the risk of recurrent thrombosis. This calculation typically considers size and location of the clot, if the clot was provoked, and any number of congenital or acquired markers of thrombophilia. This manuscript asks the question, does the presence of antiphospholipid antibodies (APA) increase recurrence risk after a first unprovoked VTE? APA are a heterogenous group of acquired autoantibodies directed at plasma proteins. The antiphospholipid syndrome (APS), oversimplified, is a positive APA associated with a positive clinical manifestation of thrombosis. The authors prospectively followed a panel of APA in a cohort of 307 patients with first unprovoked VTE, specifically looking at recurrence rates in the 290 patients who stopped anticoagulant therapy in response to negative D-dimer. They concluded that having the same type of APA on 2 occasions or having >1 type of APA on the same or different occasions is associated with recurrent thrombosis in patients with a first unprovoked VTE who stop anticoagulant therapy in response to negative D-dimer tests. APA appears to be an independent predictor of recurrence in patients with unprovoked VTE and may indicate the need for prolonged anticoagulant therapy.


Symptomatic and refractory pediatric ITP remains a difficult diagnosis for the pediatrician and pediatric hematologist. The impact on quality of life can be debilitating and the historic toxicity of first and second line therapies can be substantial.
The introduction of thrombopoietin receptor agonists TPO-RAs (specifically eltrombopag as the only FDA approved drug in children) has provided one therapeutic option with reasonable efficacy and minimal side effects (as demonstrated in the PETIT and PETIT2 trials). This review article details the mechanism of action of TPO-Ras, reviews clinical trials completed to date, and outlines the future applications of these medications, including expanded use as upfront therapy in pediatric ITP.


A pediatric hematologist will be called weekly to evaluate benign neutropenias of childhood. It can be difficult to know which children require a more aggressive laboratory evaluation and which can be clinically observed. Free and/or cell-bound neutrophil autoantibodies can be detected by flow cytometry with both direct- and indirect-granulocyte immunofluorescence tests (D-GIFT and I-GIFT), but the diagnostic utility of these studies remains questionable. The authors address the issue through a prospective study to evaluate a broad group of children presenting with neutropenia. They conclude that D-GIFT evaluation can improve the diagnostic accuracy of pediatric neutropenia, but that improvement of cell-bound antibody detection is needed to decrease false positive results.

**AAP Digital Transformation Initiative**

We are well underway with the Board approved Digital Transformation Initiative (DTI) and the AAP has received helpful feedback, from many of you, about the need to consistently communicate initiative current happenings. This letter serves as our first update geared specifically towards AAP sections and councils to share important DTI updates along with details on how the initiative affects the important work you do on behalf children and your members. Please look for updates on a quarterly basis.

For those who are new to DTI, the Board of Directors approved this bold initiative in 2017 to respond to your needs and concerns regarding our digital landscape. The overarching plan is to retool, revamp and consolidate the AAP's digital platforms to be easier to use and access. This means they will be more member-centric and highly collaborative so that you all can focus on what really matters: the health of all children.

The DTI will evaluate and improve digital platforms and products across the Academy that will result in improved user experiences across groups, including early career pediatricians, generalists, subspecialists and the public. These improvements are designed to bridge the gap between our members and their desire for learning and access to resources, so they can better care for children. The path to bridging this digital gap includes the following:

- Provide an online community that inspires knowledge-sharing and advocacy (connect)
- Present a unified member experience that builds trust and credibility among members and the public (simplify)
- Improve products and tools to facilitate learning and easy consumption of personalized and searchable content (personalize)

DTI is a multiyear, iterative process for the Academy. The team continues to address your feedback and is rolling out fixes, changes, and features that have been prioritized as highest value on a continuous basis. With that in mind, here are a few updates and important milestones:

- The new Search platform has been live for just a few months. Usage is averaging 10,000 searches per weekday and 4,800 searches per day on weekends. This is significantly higher than the old search application. The new search provides users many more ways to filter and find just what they are looking for. The search app is also using machine learning and we are working to boost most relevant search results.

We also received feedback from members about the difficulty in finding Red Book content. To help improve searchability, we have created a new context dropdown for Red Book Online and added section and appendix filters to match Solutions. We have also included chapters and page numbers so that the content can be referenced to the print version.
AAP Digital Transformation Initiative  Continued from Page 14

• **My Account** is your central location for member demographics, personal preferences, and purchasing/subscription history. We have analyzed the feedback on the new My Account prototype received from member leaders at the 2018 Annual Leadership Forum (ALF) and are making changes to enhance the order history and member contact information components.

• **Transcripts** serve as a centralized record of all individualized Continuing Medical Education and Maintenance of Certification part 2 and 4 credits. We have analyzed feedback on the new Transcripts platform received from member leaders at the 2018 ALF and are making updates to ensure all transcripts include real-time data that reflects all individual activities. Look for a launch announcement of the new Transcripts functionality sometime this summer!

• As we continue to focus on improving the user experiences for members through DTI, a related activity is occurring to the content on AAP.org. Over the last several months, section and council web pages have been refocused to highlight the work your group does and now serve as a key recruitment tool to increase awareness of and membership in AAP groups. In addition, **Collaboration sites** are being set up to serve as the new “home” for your group work and the place where the core content and work product of your section and council resides. It is on these Collaboration sites where you will have the freedom to post and share member-specific content in a wide variety of ways including via document sharing, image libraries, collective calendars, discussion boards, archives, and much more. We understand how important the work you do is and how the content you create can serve as a demonstration of member value, and are pleased to offer Collaboration sites as a platform by which you can showcase your work to your members. The Academy is committed to working with you as you build out your Collaboration sites and welcomes your feedback to learn how we can continue to meet the needs of your section or council.

To find more information and updates please visit any AAP.org webpage, scroll down to the very bottom and click on Digital Transformation Initiative in the bottom right.

**What you can do to help:**
The search platform is setup such that the more searches you do, the better it will respond over time. We encourage you to try AAP.org search and to submit feedback via the “Provide Feedback” button on the right-hand side of the screen. You can also use our Search Quick Start Guide to learn more about all of the new Search capabilities available to you. If you have suggestions or questions about AAP.org beyond the search functionality, please write to us at digitaltransformation@aap.org.

Thank you for your continued support and patience as we make these improvements.

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**Sickle Cell Disease Coalition (SCDC) Update**

The mission of the **SCDC** is to amplify the voice of the SCD stakeholder community as well as promote awareness and improve outcomes for individuals with SCD. The Coalition will focus on promoting research, clinical care, education, training, and advocacy. The SCDC will serve as a platform to encourage stakeholders to work together to develop and implement important projects and activities that will ultimately help to improve outcomes for individuals with SCD.

The AAP is a member of the SCDC and SOHO Chair, Dr. Zora Rogers and AAP SOHO Manager, Ms. Suzanne Kirkwood, currently serve as the representatives.

Previous issues of the **SCDC Update** and a subscription form to the e-newsletter are available [here](#) on the SCDC Coalition website. We encourage you to share this information with your colleagues who have an interest in sickle cell disease.
ASH Guidelines on SCD Available for Public Comment

The American Society of Hematology (ASH) is seeking comments on two draft clinical practice guidelines: *Sickle Cell Disease-Related Cerebrovascular Disease* and *Sickle Cell Disease-Related Cardiopulmonary and Kidney Disease*. Materials will be available through **November 5th** and can be found at [www.hematology.org/Guidelines-Public-Comment](http://www.hematology.org/Guidelines-Public-Comment). These are the second and third of five forthcoming guidelines on SCD. Anyone is welcome to review the draft recommendations and submit comments, including ASH members, non-member physicians and researchers, allied professionals, representatives of medical societies, industry and insurance companies, patients, caregivers, and members of the public. Feedback received will be provided to the guideline panels for review. Comments will also be considered for implementation and dissemination efforts following publication, and future revision efforts. Please let your colleagues and friends know about this public comment period.

Welcome to Our New Members – Update List

If you know of others who might be interested in joining the Academy and the Section please refer them to the AAP website [membership page](http://www.aap.org). Thank you to all who have continued to support the AAP and the Section by renewing their memberships. And welcome to [new members](http://www.aap.org) of the Academy and the Section!

For Upcoming Newsletters . . .

We welcome your input and encourage you to submit ideas or information by email to Carl Allen, MD, FAAP at [ceallen@txch.org](mailto:ceallen@txch.org) or Suzanne Kirkwood at [skirkwood@aap.org](mailto:skirkwood@aap.org) for future issues of the newsletter.