NEWS FROM THE CHAIR
Alex Okun, MD, FAAP
Chairperson, Section on Home Care (SOHCa)

Happy October, SOHCa members,

I’m looking forward to seeing as many of you in Orlando that can attend our Section Program on Saturday, November 3rd from 8:00 AM - 12:00 PM.

Jointly developed with the Council on Children with Disabilities (COCWD), the program, "Demystifying the Care of Children with Medical Complexity-At Home and in the Office," features great speakers focused on what we care about and work hard at every day. See the write up, below.

Please also join me in welcoming Ms Sondra Gilbert as liaison from the AAP Family Partnerships Network. You can read about Sondra below, and please come meet her in Orlando next month.

As I finish my term as chairperson, I want to thank everyone on our Executive Committee for all they've done on behalf of our section over the last year:

- Ngozi Onyema-Melton, for managing our section activities and responsibilities day-to-day and year-to-year, and particularly for the positive, careful, sensitive and consistent way she does all that.
- Betsy Anderson and Julie Beckett, for their years of leadership in our section, the AAP as a whole and on a national level, insisting that families have a greater voice and a central place in the care of their children, and making that happen.
- Roy Maynard, for putting together presentations at NCE year after year, including the fantastic one next month; for making high tech home care available to children in need throughout his state; and for highlighting the crisis of children in need of home care services that are unavailable and, as a result, remain in hospital beyond medical need.
- Doug McNeal, for carrying the flag of advocacy for medically necessary services based on EPSDT, the importance of which greater and greater numbers of members and groups at AAP are now beginning to recognize and promote.
- Eddie Simpser, for pulling together the revised policy statement, "Financing of Pediatric Home Health Care," published last year, in collaboration with the Committee on Child Health Financing and others; for his work as liaison to the COCWD; and for running a huge facility in my home town, NYC, that helps children bridge their time from prolonged, high acuity hospitalization to care at home with needed supports; and for making available to those children and their families top quality rehabilitative services in

USEFUL LINKS
Section on Home Care Website
HealthyChildren.org

SECTION RESOURCES
Medical Necessity Letter - New Location on AAP.org
The customizable physician’s Letter of Medical Necessity for Home Health Care per EPSDT (Early and Periodic Screening, Diagnostic and Treatment) mandates is now available on the AAP Practice Transformation website, more specifically – the “Engaging Patients & Families” webpage. To access the template letter directly, please click here.

CALL FOR NEWS AND INFORMATION
What Is On Your Mind?
Members are encouraged to contribute to the SOHCa newsletter. Please submit articles to Ngozi Onyema-Melton at nonyema@aap.org. Article length should be between 300 and 900 words.

The final submission deadline for the next issue is December 1, 2018.

SECTION MEMBERSHIP
Healthcare is coming home!
The Section on Home Care aims to serve as a resource for providers and families interested in home care. This includes education for physicians, affiliate members, and others who are interested in making house calls. Encourage your
the region. Eddie rejoins our Executive Committee as a voting member right after the upcoming NCE.

- **Garey Noritz**, for his contributions as liaison from the COCWD; for the vast collection of magnificent writing he has published on complex care, home care, bioethics, palliative and hospice care and humanism; and for the care he organizes for children, youth and adults through his work in his home state.
- **Elaine Lin** and **Brian Thornburg**, with Ngozi’s support, for tripling our membership with initiatives to recruit pediatricians in training; and for their special work in home visiting, caring in the most personal and novel ways for children with a range of needs and their families from such varied backgrounds and communities.
- and **John Langley**, for his leadership in our section and throughout the AAP; and his management of home care services for children across the country. Thank you, John, for taking over the role of chairperson of our section.

Be well, and stay committed to all the good work you do.

Alex Okun, MD, FAAP
Alexokun116@gmail.com

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**WELCOME NEW PARENT LIAISON**

Ms Sondra Gilbert (Kentucky) is the Co-Director and Parent Consultant for the Family-to-Family Health Information Centers at the Commission for Children with Special Health Care Needs. She has been married for 32 years, she has 3 children with a genetic disorder and other special health care needs. She has been advocating for over 25 years for not only her children but for other children as well.

Ms Gilbert has been a Resource Specialist with over 25 years of experience in working with children and adults with special health care needs. She co-partnered to write a resource manual on *Understanding Special Education* that was distributed to families in Owensboro and Daviess county school systems.

Ms Gilbert has served on the Federal Medical Home Committee/Care Coordination. She has represented family members at the AMCHP conference and also has been a mentor to other families at this conference which is held in Washington, DC annually.

Ms Gilbert is part of Family Voices of Kentucky and Kentucky Parent-2-Parent. She has served on the Region 4 Genetic Collaboration for 9 years, which is a 7 state collation and has completed the leadership training on Medical Home and Care Coordination, and help write two manuals for families, *Partnering with your Doctor, The Medical Home Approach*, the second one was, *The Journey Through Diagnosis*.

Ms Gilbert was appointed by the Governor to represent the family of children with developmental disabilities, on The Commonwealth Council on Developmental Disabilities, and is still on this council.
Other professional involvement includes:

- Participant on Core Team for Children with Medical Complexity Kentucky State Team (KOIN’S).
- Trainer for the KY-Spin and Kentucky Department of Education instructing how to facilitate workshops.
- Wrights law training understanding and writing an (IEP) Individuals Education Plan for students with disabilities. Understanding basic education laws pertaining to the new IDEA.
- Kentucky Partnership for Families and Children Inc. Completed KPFC’s Leadership Academy
- Kentucky Partnership for Families and Children Inc. Café trainer protected factors.

Certificate of Recognition

- Commonwealth of Kentucky for extraordinary service and commitment to your peers in the Commonwealth of Kentucky which compelled a nomination for the 2007 Governor’s Award for Outstanding Volunteer Services in the Impact Adult category.

SECTION ON HOME CARE NEWS

Executive Committee Update
Congratulations to Ms Sondra Gilbert who was appointed as the new family liaison to serve on the Executive Committee of the Section on Home Care. Her term will begin on November 1st.

We are grateful to have had Ms Julie Beckett and Ms Betsy Anderson serve a term on the Executive Committee. We thank them for 10+ years of service to the Section and look forward to their ongoing involvement in Family Partnerships Network activities.

2018 AAP NATIONAL CONFERENCE & EXHIBITION

The 2018 National Conference & Exhibition (NCE) will take place November 2-6, 2018 in Orlando, FL.

This year, the Section on Home Care has developed an exciting new program jointly co-sponsored with the Council on Children with Disabilities (COCWD). For detailed information regarding the program please review the agenda below.

H1014 Joint Program: Council on Children with Disabilities and Section on Home Care
Date: Saturday, November 3, 2018 | 8:00 AM - 12:00 PM
CME: 3.5
Location: Hyatt Regency Orlando Hotel
Room: Plaza International Ballroom J
Faculty
Deborah Boroughs, Jeffrey Lee Goldhagen, Jennifer Lyn Lail, Nancy Speller

Description
Demystifying the Care of Children with Medical Complexity—At Home and in the Office

Children with medical complexity are children with chronic health problems that affect multiple organ systems and result in functional limitations, high health care utilization, and often the need for medical technology. This council/section program will improve clinician ability to provide medical and psychosocial care for children with medical complexity in the office, home, and alternative settings such as long-term care facilities and medical day care. Additionally, participants will recognize medical devices used by children with medical complexity, such as feeding tubes and tracheostomies, and will have the opportunity to apply their skills through a hands-on skills lab with these medical devices.

Agenda

8:00 AM  Welcome and Introductions  
Moderators: Garey Noritz, MD, FAAP; Roy Maynard, MD, FAAP

8:15 AM  Who are Children with Medical Complexity?  
Jeffrey Goldhagen, MD, MPH, FAAP

8:45 AM  Questions and Answers

9:00 AM  Nuts and Bolts of Home Care Nursing  
Deborah Boroughs, RN, MSN

9:30 AM  Questions and Answers

9:45 AM  Complex Care Clinics: How to Work in Them and With Them  
Jennifer Lail, MD, FAAP

10:15 AM  Questions and Answers

10:30 AM  Arnold J Capute Award Presentation  
Recipient: Paul S Carbone, MD, FAAP

10:45 AM  Medical Device Skills Lab  
COCWD and SOHCa Executive Committee Members

11:15 AM  Advocating for Home Care Services at an Individual and Societal Level  
Nancy Speller, MS, RN

11:45 AM  Questions and Answers

12:00 PM  Closing Remarks/Adjourn

Other Sessions of Potential Interest at the 2018 NCE
Include the Following:

V1066 They're Your Patients, Too: Children With Special Needs Initiatives at the AAP  
Saturday, November 3 | 12:30 PM - 1:30 PM
Meet the authors of recently published clinical reports from the AAP Council on Children with Disabilities on pain assessment, shared decision-making, and medical complexity. Learn more about council activities focused on ensuring issues specific to children and youths with special health care needs are integrated into AAP initiatives.

Not designated for CME credit

**Topic(s): Children with Special Needs**

**2054 Fetal Alcohol Spectrum Disorders: Treatment Across the Lifespan**
Sunday, November 4 | 9:30 AM - 10:15 AM

This session will review concerns and treatment options for patients with one of the fetal alcohol spectrum disorders at the infant, toddler/preschooler, school-age, and adolescent and teen stages. In addition to management of these patients in the primary care setting, faculty will address neurobehavioral and complex medical concerns, including pharmaceutical and therapeutic considerations, and behavioral and educational interventions. Support services, resources for parents and caregivers, and transition from pediatric to adult care also will be discussed.

**Faculty**
Jessica Foster, MD, MPH
Director, Division of Developmental Behavioral Pediatrics
Akron Children’s Hospital

**Topic(s): Endocrinology**

**F2118 What’s New in Type 1 Diabetes Care?**
Sunday, November 4 | 4:00 PM - 4:45 PM

The management of young children and adolescents with type 1 diabetes mellitus is challenging. Primary care providers need to understand the technology used to improve blood glucose control and quality of life. Faculty will discuss how pediatricians can partner with pediatric endocrinologists to improve comprehensive care in this patient population.

**Faculty**
Michael Haller, MD, FAAP Professor and Chief, Pediatric Endocrinology
University of Florida College of Medicine
Gainesville, Florida

**Topic(s): Disaster Preparedness**

**I2116 Harvey, Irma, Maria, and More: Disaster Recovery Issues**
Sunday, November 4 | 4:00 PM - 5:30 PM

This session will help pediatricians better prepare for and respond to disaster and its aftermath, focusing on response and recovery issues identified during recent hurricanes. Attendees will learn why disaster preparedness is important for all pediatricians, how to prepare and mitigate risk, and what issues might arise during prolonged recovery from disaster (including mental health issues and infectious disease outbreaks). The session will focus on improving pediatricians’ abilities to care for themselves and their patients and promote mental health and community resilience.
**Faculty**
Scott Needle, MD, FAAP, Medical Director
Healthcare Network of Southwest Florida
Naples, Florida

**Topic(s): Telehealth**
**S2133 Why Should I Be Doing Telemedicine? Specialist and General Pediatrician Perspectives**

Sunday, November 4 | 4:00 PM - 5:30 PM
This session will explore the use of telemedicine in the general pediatrician's and specialist's office. Faculty will discuss how to develop a telemedicine program and issues involved, including equipment, coding, and insurance coverage and negotiations. The role of telemedicine in addressing disparities in access to care for medically underserved children in rural and urban communities will be explored.

**Faculty**
James Marcin, MD, MPH, Professor, Pediatric Critical Care
University of California Davis Children's Hospital
Sacramento, California

**Topic(s): Hematology/Oncology**
**F3027 Childhood Cancer Survivors: Long-Term Issues**
Monday, November 5 | 8:30 AM - 9:15 AM

Based on current research in childhood cancer survivors, new information will be presented on risk factors associated with late effects cancer therapy. Prevention, screening, and intervention strategies for the pediatrician will be addressed.

**Faculty**
Melissa Hudson, MD, Director, Cancer Survivorship Division
St Jude Children's Research Hospital
Memphis, Tennessee

**Topic(s): Pulmonology, Neurology  Sponsor(s): Section on Pediatric Pulmonology and Sleep Medicine, Section on Neurology**
**H3015 Joint Program: Section on Pediatric Pulmonology and Sleep Medicine and Section on Neurology**
Monday, November 5 | 8:00 AM - 12:00 PM

Too Weak to Breathe: Managing Respiratory Complications of Neuromuscular Disease Muscular dystrophy and spinal muscular atrophy are old problems with new treatments that get to the basic genetic and molecular defects of the diseases. This program is for primary care physicians, hospitalists, pulmonologists, neurologists, and other specialists who care for children with neuromuscular disorders with risk of respiratory infections, aspiration disorders, sleep-disordered breathing, and respiratory insufficiency and failure. Attendees will learn to identify respiratory complications and when to refer and coordinate patient care.

**Faculty**
Susan Iannaccone, MD, Professor
Every few months, there seem to be news reports announcing the demise of fee-for-service payments and how payments will be based on value and the accountable care organization (ACO) structure. Until these actually arrive, various interim “quality” payments are becoming a larger part of physician payment. Faculty will discuss ACO structures, the value concept, and interim quality measures.

Faculty
Angelo Giardino, MD, FAAP, Chair/CMO
University of Utah/Intermountain Primary Children's Hospital
Salt Lake City, Utah

S3121 The Pediatrician's Role in Preoperative Evaluations for Children With Medical Complexity
Monday, November 5 | 4:00 PM - 5:30 PM

This session will provide an overview of how to optimize children with medical complexity for surgery and resources for these children in preoperative inpatient and outpatient settings. Faculty will review the preoperative interview, strategies to identify risk factors for perioperative complications, and indicators for when a surgical procedure should be cancelled or postponed. Case scenarios will be used to improve attendees’ understanding of preoperative management and facilitate communication among surgeons, anesthesiologists, subspecialists, pediatricians, and families.

Faculty
Karen Fratantoni, MD, Attending Pediatrician
Children's National Health System
Washington, District of Columbia
Anjna Melwani, MD, FAAP, Pediatric Hospitalist
Children's National Health System
Falls Church, Virginia
W4032 Emergencies in the Technology-Dependent Child: What Every Pediatrician Should Know (Repeats as W4074)
Tuesday, November 6 | 8:30 AM - 10:00 AM

This workshop will begin with an overview of devices used by technology-dependent patients for neurologic, respiratory, and nutritional needs. Participants then will rotate through four hands-on stations that simulate a complex care emergency. A leader will present a case and facilitate the group as they work through each scenario, manipulate devices, and ask questions. Key concepts and trouble-shooting techniques will be reviewed during debriefing. As a large group, participants will develop strategies to implement safety principles learned in the workshop.

Faculty
Priti Bhansali, MD, Pediatric Hospital Medicine Attending Physician; Associate Program Director, Pediatric Hospital Medicine Fellowship Children’s National Medical Center Washington, District of Columbia
Neha Shah, MD, MPH, Associate Professor of Pediatrics Children’s National Health System The George Washington University School of Medicine and Health Sciences Washington, District of Columbia

Topic(s): Community Pediatrics
S4085 Addressing the Impact of Racism on Child Health and Development: Supporting Children, Families, and Providers
Tuesday, November 6 | 4:00 PM - 5:30 PM

This seminar will address the impact of racial bias and racism on children’s health and well-being. Research will be presented on the connection between racial bias/racism on children’s health, development, educational achievement, and other outcomes. Participants will learn strategies to promote positive development of self-identity among minority youth, including the concept of racial socialization. Guidance also will be given on partnering with community organizations to help families navigate race-related concerns that impact children’s well-being.

Faculty
Tiffani Johnson, MD, Assistant Professor of Pediatrics Children’s Hospital of Philadelphia Philadelphia, Pennsylvania
Joseph Wright, MD, MPH, FAAP, Chief Medical Officer, UM Capital Region Health University of Maryland Medical System Washington, District of Columbia

For more information about the NCE or to register visit: www.aapexperience.org.

Questions, comments, feedback? Please email us at nonyema@aap.org.