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2017 Legislative Priorities: Final General Assembly Report

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Virginia Chapter Lobbyist

The 2017 Virginia General Assembly session adjourned on Saturday, February 25. While this was a "short session," the legislature was still very productive and considered over 2,000 bills in 46 days. The last agenda item they completed was voting on the final budget conference report (http://budget.lis.virginia.gov/amendments/2017/1/HB1500/Introduced/CR/), which passed the House 99-1 and 40-0 in the Senate.

This was Governor McAuliffe's final legislative session and his last opportunity to get his policy priorities through. It is also an election year, with the entire House of Delegates and the statewide offices up for election in November.

As usual, healthcare continued to be a focus for the legislature. They were hesitant to pass any major reform bills due to the uncertainty at the federal level with the Affordable Care Act and have created a legislative work group to monitor the changes in the ACA and determine their impact on Virginia.

One issue that was debated extensively is whether to reform the Certificate of Public Need program. Similar to last year, there was support in the House for reform, but the efforts came to a halt in the Senate. However, the Senate has said they will study this issue again over the next year, in context with the other changes coming down from the federal level.

Mental health reform remained a consistent topic of discussion, but without a lot of true reform occurring. Money was included in the budget to implement "same-day access" standards at Virginia's community services boards- $6,200,000. Also, the budget includes a $5M increase in permanent supportive housing funding, which is designed to help get patients out of state hospitals and prevent unnecessary hospitalizations, homelessness, or interactions with the criminal justice system. Finally, the General Assembly allocated a total of $500K for two different studies of the mental health system- half to the Secretary of HHR and then the other half to the Deeds Commission, which has been extended for another two years.

The opioid epidemic was a focus of the 2017 legislature, the need for changes supported by preliminary numbers from VDH showing a 33 percent increase in opioid overdoses in 2016 with over 1,000 deaths. As part of the opioid conversation, VA AAP supported bills that focused on the most vulnerable victims of the opioid epidemic- babies suffering from Neonatal Abstinence Syndrome (NAS). Below are the NAS related bills and budget items:

HB 1467 (Greason)/SB 1323.(Carrico) SUPPORT. Requires the Board of Health to adopt regulations to include neonatal abstinence syndrome on the list of reportable diseases. PASSED

HB2162 (Pillion) SUPPORT. Creates a work group to study barriers to treatment of substance-exposed infants in the Commonwealth. PASSED

Budget Item 294#1c (Dunnavant) SUPPORT. VDH to establish and administer a Perinatal Quality Collaborative to work to improve pregnancy outcomes for women and newborns by advancing evidence-based clinical practices and processes through continuous quality improvement with an initial focus on pregnant women with substance use disorder and infants impacted by NAS. PASSED

The physician community was able to successfully divert bills that sought to establish statutory prescribing limits to instead direct the Board of Medicine to issue emergency regulations for opioid prescribing. In addition, a bill passed that authorized a new needle exchange program in at-risk communities; others made several changes to increase the availability of naloxone, an overdose-reversal drug. Another will require that all opioid prescriptions be made electronically

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by 2020.

HB2167 (Pillion) & SB1180 (Chafin) HB1885 (Hugo) & SB 1232 (Dunnavant) SUPPORT: Opioid Guidelines & Prescription Monitoring Program Requirements

- **All four bills have passed and have either been signed by the Governor or are on his desk awaiting his signature.**
- HB2167 & SB1180 directs the Boards of Medicine and Dentistry to adopt regulations for the prescribing of opioids and products containing buprenorphine.
- HB1885 and SB1232 (as amended) will mandate physicians check the Prescription Monitoring Program any time they prescribe a controlled substance containing an opioid for 7 or more days.

Every year we face bills that seek to change the scope of practice for mid-level providers. This year was no different, although we did not have any bills put forth by the nurse practitioners as we had originally expected. Instead, we saw a bill that was the first in the nation- a bill to create a doctorate of medical science put forth by Lincoln Memorial University in Tennessee. We were able to defeat the bill this year by asking for it to be studied further, but the concept has support from high ranking Republican Senators, including the chairman of the Senate Education and Health Committee. We will need to monitor the study closely.

SB 1327 (Carrico) OPPOSE. Doctorate of Medical Science: DEAD for the YEAR

- Passed by indefinitely in Education and Health and will be studied over the summer in a special legislative subcommittee. Dead for the year.

- This brand-new degree is untested and not yet accredited. The first class just started in the Fall of 2016 and we believe it is far too early for Virginia to grant a new license for such a nascent profession.

Other Bills VA AAP Followed in 2017:

SUPPORT HB 2210 (Yancey) Supporting Mothers Who Breastfeed: **DEAD for the YEAR**

- This bill was tabled in House Commerce and Labor Committee and is dead for the year.
- This bill would require employers to provide reasonable unpaid break time each day to express breast milk for one year after the child's birth and make reasonable efforts to provide a room or other location in close proximity to the work area, other than a toilet stall, where such an employee can express breast milk in privacy.

OPPOSE HB2030 (Freitas)/HB2368 (Morris) Food Safety; Sale of Raw Milk: **DEAD for the YEAR**

- These bills failed to report, 6-Y 15-N in House Agriculture Committee even after extensive amendments and the creation of an inspection process for the sale of raw milk. We continued to opposed the bill.

- Oppose legislation that allows people to buy farm-produced food directly from farms- without any

SUPPORT HB1757 (Dudenhefer): **This bill was TABLED** in House Appropriations because of the inherent cost for localities to implement this bill. This bill would require at least one school nurse in every elementary, middle and high school in a school division.

SUPPORT HB1829 (Dudenhefer): **PASSED** both houses and is a technical fix to Gwyneth's Law that we supported in 2013 that required CPR training for teachers and students. This bill added the hands-on CPR requirement to the teacher training that already existed for students.

SUPPORT HB2209 (O'Bannon) & SB1561 (Dunnavant): PASSED both houses unanimously and the money was included in the final budget. This bill would create an ED Care Coordination Program that will utilize a proven software program to be used by hospitals and in primary care physicians' offices, to identify complex, high-utilizing Medicaid patients based on data analytics and notify primary care providers in real-time as to their patients' presence in the ED, all to better coordinate patients' care.

SUPPORT HB1813 (Leftwich) / SB1513 (Wagner): Assignment of Benefits Bills **DEAD for the YEAR**

HB 1813 passed the House Commerce and Labor Committee, 14-7, but after significant opposition was raised by the Health Plans, the patron asked for the bill to be re-referred to committee to avoid a negative floor vote and to keep us in a favorable position and is dead for the year. The Senate bill failed to report in Senate Commerce and Labor and the patron asked for the bill to be referred to the Health Insurance Reform Commission to be studied in the interim.

MONITOR HB 1408 (Ware): Vision Screening in Schools **PASSED**. VA AAP asked for an amendment to the bill that allowed vision screenings done by physicians to count as the required school screenings. The amendment was accepted and the bill has passed as a bill that is now permissive rather than mandatory, allowing schools to keep the current practice or use the new option. No money was included in the budget to offset the costs to the school systems.

SUPPORT: SB868 (Favola): **PASSED as amended**. This bill required that the state Department of Social Services promulgate regulations requiring local social service agencies to investigate complaints of child abuse and neglect for children under the age of 2 within 24 hours of receiving such complaint.

Final Budget Items VA AAP Followed

Budget Item 30#2c:
This amendment adds language directing the Joint Commission on Health Care to examine and identify strategies to increase public awareness of the risks and concerns related to the use of psychiatric medications used to treat Attention Deficit Hyperactivity Disorder (ADHD) and other disorders.

Budget Item 291#1c: This amendment requires the state teaching hospitals to work with the Department of Health and Division of Vital Records to fully implement use of the Electronic Death Registration System (EDRS) for all deaths occurring within any Virginia state teaching hospital's facilities. Full implementation shall occur and be reported, by the Division of Vital Records, to the Chairmen of the House Appropriations and Senate Finance Committees by April 15, 2018, in alignment with Vital Records plans to promulgate and market the EDRS.

Budget Item 302#1c: This amendment put forth by MSV directs the Dept of Health Professions to develop and implement a real time prescription drug monitoring demonstration program with Medicaid prescribers using HITECH funds.

Budget Item 30#1c: This amendment directs the Joint Commission on Health Care to study options for increasing the use of telemental health services in the Commonwealth.

Budget Item 1#13c: This amendment adds language creating a joint subcommittee of the House Appropriations and Senate Finance Committees to respond to federal health care changes, provide oversight of the Medicaid and children's health insurance programs, and provide oversight of Health and Human Resources agency operations.

The legislature will reconvene on Wednesday, April 5. They will review all the Governor's actions on bills, including the budget and vote whether to accept or reject his vetoes and amendments. Overall, it was a positive legislation session for VA AAP. We don't anticipate any issues to arise during veto session, but will update you if anything should change.

President's • MESSAGE

Sam Bartle, MD, FAAP *President Virginia Chapter American Academy of Pediatrics*

"For the times they are a-changing" Those of us who are more "time experienced" (a nice way of saying "old") may recognize the title above. It's a song by the Nobel laureate, Bob Dylan. Anyone who enjoys music and knows history will attest to how Mr. Dylan defined a generation during a time of great change. Any good music is timeless. This is no exception.

Unless you have been living under a rock, you know that healthcare has been very much in the forefront of many news stories recently. Clinical medicine is not changing, but how it will be delivered in the near future is in question. Will the Affordable Care Act be repealed? Will it be replaced? There is discussion about making major changes in the Medicaid program, the largest provider of healthcare coverage for non-insured children in this country. There is concern that the CHIP program is at risk of not being funded as it comes up for renewal this fall. Approximately 70 million children in the U.S. receive healthcare that is covered by Medicaid, with CHIP supporting an additional 8 million children.

In Virginia, more than 651,000 children receive healthcare covered by Medicaid and FAMIS (Virginia's CHIP program). In the current fast-changing, often highly polarized political climate, many providers and patients' alike worry about the extinction of programs that are critical to the care of our precious children. The only certainty about it all of this is the uncertainty what will happen.

On February 27 & 28, I had the privilege of representing the Virginia Chapter at the AAP Fly-In held in Washington, DC. This was an opportunity to visit Virginia's members of Congress and advocate for the continue support of the programs the help children receive the healthcare they deserve. It was an opportunity to remind our representatives of the importance of maintaining and improving the health of the children of our state and the nation. The goal of the discussions with the members of the House of Representatives and Senate was to communicate the importance of the principles of access to healthcare that as pediatricians believe to be part of the foundation of having healthy children. The principles endorsed by the AAP are that every child should receive care in a medical home; that quality healthcare is a right for all children regardless of their family income; every child must have access to the quality healthcare they deserve; healthcare plans must have comprehensive age appropriate benefits; and payment rates should assure that children receive all needed services. Through continued support of the Medicaid and the CHIP programs, improving immunizations and protect the Affordable Care Act, children can have access to the healthcare they need and deserve.

The timing of these visits could not have been better. Around the time of this advocacy event, President Trump commented at a meeting of the National Governors Association that healthcare was "an unbelievable complex subject." Yes, healthcare is *definitely* complex. As pediatricians, we know of the importance of providing and maintaining the health of children. The comprehensive and preventative care defined under Medicaid as the Early and Periodic Screening, Diagnostic and treatment (EPSDT), considered the standard of care for children, and just scratches the surface of how complex healthcare for children is. As pediatricians, we deal with the complexity of child healthcare daily.

It's so important to let our elected officials know that we not only understand the complexity of child healthcare, but also that it is considered necessary to continue to provide it. More importantly, those in Congress and the White House considering making changes in healthcare need to know that it is essential to continue to be able to provide access to this medically-necessary care. A large share of at-risk children depends on the healthcare covered by Medicaid and FAMIS. Of all Medicaid/FAMIS enrollees in Virginia, 67% are children and almost three-quarters, 73% of children living in or near poverty are covered by Medicaid/FAMIS. All children in foster care receive their healthcare rely on public coverage. Medicaid/FAMIS covers care of 32% of all infants, toddlers and preschoolers during the early years of development and school readiness. Medicaid helps children grow and reach their full potential. Children covered by Medicaid, compared to those not covered from similar backgrounds, miss fewer days of school, perform better in school, more likely graduate from high school, grow up to be healthier adults, and earn higher wages. Medicaid has also been proven to contribute to declines in infant and child mortality.

Medicaid is a federal-state partnership that guarantees coverage for these vulnerable children. Restructuring or eliminating Medicaid will place the children that are covered at risk. Unfortunately, cutting funding risks pitting children's needs against other vulnerable groups, including individuals with disabilities and the elderly. Converting medical to a block grant system risks funding shortfalls in times of economic downturns. It also risks shifting the financial risk to the state to fill gaps in funding needs. If any changes are made, there is concern of increasing the cost-sharing for the families least able to afford it, in addition to decreasing eligibility; these proposals would decrease the means to provide the care under EPSTD standards. Any new program needs to satisfy two questions. Does every child maintain access to coverage? Does every child maintain access to medically necessary care?

I encourage each chapter member to contact their representative in both Congress and the Virginia General Assembly to encourage them to continue to support Medicaid and FAMIS. Even better try to meet with your representative, delegate and senators to discuss the issue of Medicaid and FAMIS, explaining the need to keep it and not risk changing it. It is vital that our representatives hear this message from physicians. If we do not speak for children, who will? If changes are to happen, let us be part of who directs it.

To paraphrase another great voice from the 60's, John Lennon: Give Peace and Kids a chance!

Sam Bartle, MD, Virginia Chapter President with Karen Remley, MD, AAP CEO/Executive Vice President during AAP Chapter Fly-In. Dr. Bartle along with other chapter presidents traveled to Washington to share their insights and expertise and to speak up on behalf of the children in their state.

Children's Hospital of The King's Daughters and the
American Academy of Pediatrics, Virginia Chapter

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UCAN! A New Community Asthma Program for the Richmond Area

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Objective: The reader will be able to recall demographic contribution to variations in asthma outcomes; describe programs that have successfully improved asthma outcomes vs minority children and recall the objectives of the CHoR UCAN program
ACGME Competencies: *Patient Care, Medical Knowledge*

In urban areas such as Richmond, the number of children suffering from asthma is much higher than in the surrounding areas. This fact takes on a special meaning for Richmond, which has been declared the "#1 most challenging place to live with Asthma" for 3 of the last 5 years by the Asthma and Allergy Foundation of America Capitol Report.

Far too many studies show that childhood asthma disproportionately affects underrepresented minority populations. There are racial and ethnic differences in asthma prevalence and severity, emergency department (ED) and outpatient visits, and hospitalizations. Minority race/ethnicity and socioeconomic status are independent and synergistic risk factors for mortality, morbidity, and excessive health care utilization related to asthma. Issues such as socioeconomic status, housing quality, population density, stresses related to living in an urban area, lack of family and community support, environmental tobacco smoke exposure, and rodent and cockroach-infested living areas are contributing factors. Disparities also exist with access to medical care, use of health care services, asthma knowledge and health literacy in general, asthma diagnosis and treatment, inadequate medication prescription by clinicians, and parental adherence and disease self-management.[1]

Childhood asthma is a disruptive and costly disease that imposes a heavy time and resource burden on both families and communities each year.[2] The economic burden of asthma falls disproportionately onto Black and Hispanic families, who have higher rates of hospitalization and emergency department (ED) visits than white families[3], for all the reasons outlined above. But along with the health and economic consequences of having childhood asthma, there are non-tangible lifestyle effects as well. Asthma is a leading cause of absenteeism from school, and, for parents, absenteeism from work. Furthermore, children with asthma have been said to experience loss of self-esteem and disruption of interpersonal relationships with friends, siblings, and parents.[2]

A number of studies over the last decades have shown that effective approaches exist to make an impact on this vulnerable population. Programs that have had success move beyond the traditional fee for service clinic-based care into the development of asthma-specific medical homes that provide programmatic social as well as medical support, and also introduces community-based interventions to address the Social Determinants of Health.

The multi-phasic National Cooperative Inner-City Asthma Study (NCICAS) was undertaken in the 1990's through a Congressional directive to assess the factors related to asthma morbidity in inner-city children, and to devise and test a feasible intervention strategy aimed at reducing morbidity and improving outcomes. It was recognized that while asthma education and self-management interventions were effective in the short term for high-risk inner-city children, difficulties in maintaining long-term adherence with a care program limited usefulness in the long-term. The NCICAS intervention strategy was based on a social-environmental model of disease management aimed at the child, the care giver, and the family to effectively and efficiently provide comprehensive asthma health care services to improve outcomes.

The intervention involved the use of social workers deployed as asthma counselors (ACs) to coordinate asthma care, as well as a program to detect and control environmental exposures. The study found that the social worker-based intervention significantly improved asthma symptoms for a relatively modest overall increase in costs when compared with other asthma care. In a sub-group of children with more severe asthma, the intervention was substantially more effective and reduced the total cost of medical care. Most interventions require behavioral changes on the part of children and their families to improve adherence or to make lifestyle changes. Unfortunately, this can be challenging for many families based on perceived or actual limitations.[4]

In 2008, Dr. Michelle Cloutier designed and initiated the Easy Breathing Program in Hartford, Connecticut. This program consisted of four major elements: a survey, a provider assessment, an asthma treatment selection guide, and an asthma treatment plan. A fifth element, the assessment of asthma control, was added after the release of the 2007 NAEPP Export Panel Report 35. The Easy Breathing Program was successfully translated into a community setting with significant and sustained decreases in asthma-related hospitalization and emergency-department visits. The program was effective in reducing hospitalizations and emergency-department visits in Medicaid-enrolled children in both urban-based and private practices, and was used by a large number of practitioners in the community who enrolled significant numbers of children. Results from the program show enrolled children experienced a 35% decrease in overall hospitalization rates, a 27% decrease in asthma ED visits, and a 19% decrease in outpatient visits.6 A major focus of the Easy Breathing program was the appropriate use of inhaled corticosteroids (ICS) in children with persistent asthma, along with a written asthma treatment plan. This component was included because of findings that despite the demonstrated benefits of ICS use in managing asthma, ICSs were under prescribed and underused by primary care clinicians and their patients. Additional results from the Easy Breathing program study show that asthma –related costs among urban children could be reduced when primary care clinicians implemented a simple disease management program. Improved health, as evidenced by decreases in outpatient visits, hospitalizations, and ED visits, was associated with savings for public payers, including Medicaid managed care plans.[5]

Improving Pediatric Asthma Care in the District of Columbia program (IMPACT DC) started in 2001 to lessen the need for emergency room visits and hospital stays by educating patients and families about ways to manage asthma, and connecting them with valuable resources in the local community. The award-winning program continues to serve as one of eight sites of the Inner City Asthma Consortium (ICAC). The cornerstone of the IMPACT DC program is their clinical and educational inter-

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ventions, targeted to children with frequent ED visits, hospitalizations, missed school days, and other markers of poorly controlled asthma. The program's goal is to steer children away from episodic use of the ED for their asthma management, and towards more effective primary long-term asthma care and healthier lives. IMPACT DC provides services directly to families, but also works with schools, local communities and health care systems. The clinic typically sees children within two weeks of an ED visit or hospitalization for an acute exacerbation, or by referral, for a 90-minute visit where the family meets with an asthma educator and a physician or nurse practitioner. Taking advantage of the 'teachable moment' that naturally occurs after the crisis of an asthma attack, clinic staff focus on medical care, environmental modification/trigger control and care coordination.[7]

A number of other successful community asthma programs have been created around the country, including in Boston, New York, and Memphis (the latter our primary competitor for "Asthma Capitol" status). Here in Richmond, CARMA (Controlling Asthma in the Richmond Metropolitan Area) was initiated in 2001 with grants from the CDC and NIH to the Central Virginia Asthma Coalition and Bon Secours Foundation.[8]

Its initial goals included school nurse and day care staff training on asthma management and trigger remediation and medical office-based quality improvement of asthma care, along with home-based asthma-education and trigger-reduction components.[9] The program continues to offer free services to children between 2-18 that include home visits and education to identify asthma triggers, teach devices and review medications and asthma action plans. Care coordination for children seen in the ED or hospital starts with one-on-one education offered to the child and parents.[10]

The YoU CAN Control Asthma Now Program, or UCAN, is stepping in to meet the needs of Richmond children suffering from Asthma. The Children's Hospital of Richmond Foundation, recognizing the continuing gaps in care and ongoing need of Richmond's minority children, has provided seed funding for this program based out of the Children's Pavilion Pediatric Pulmonary clinic whose goal is to provide expert asthma care with an appreciation for the need to address contextual social and economic challenges faced by this population. The name UCAN is meant to emphasize a positive message of empowerment and to raise expectations among patients and families for what it means to have adequate control of asthma symptoms. The UCAN program is based on a case-management approach that addresses, from a family perspective, their need for appropriate and personalized medical treatment, education to improve asthma disease self-management, and services to counter adverse social determinants of health.

With top of the line medical care and focused patient education children are able to gain control of asthma symptoms and live active, healthy lives. The UCAN team is made up of CHoRatVCU Pulmonary doctors, ancillary nurses, respiratory therapists, and a dedicated nursing case manager and social worker. The entire family receives support to learn about asthma, understand the medication used to control asthma, identify triggers and also to help look at environmental factors that affect health. We work with partner agencies, Richmond Healthy Homes (a Richmond Health Department program), the Medical-Legal Partnership, and Family Lifeline, to help families determine the presence of asthma triggers in their homes, advocate for families who are living in substandard apartments or houses with help from the medical-legal partnership, and provide referral services to families in financial or housing crisis.

Our target population consists primarily of low income minority children who have been hospitalized at CHORatVCU for asthma and show evidence of poor chronic asthma management and control. Patients can also enter the UCAN program by referral from the Hospital Emergency Room and from community health care providers. The first step in receiving services from UCAN is an appointment with a doctor in the Pulmonary medicine clinic at CHORatVCU. A personalized treatment plan is then developed for each child which includes proper assessment and diagnosis, appropriate medication, education in disease management, environmental evaluation, and support to address family or community barriers to optimal asthma management.

With the coordination of a Nursing Case Manager and Social worker, asthma education is provided face-to-face during hospitalization and also during clinic visits. Follow-up is done via telephone that includes giving assistance with medications and assessments of socio-economic barriers that may be a hindrance to children living with asthma. Support and education is provided to help families overcome obstacles to manage appropriate daily care.

Specific services include:

- Patient centered, culturally sensitive, relationship-based medical care
- Consistent providers
- Frequent, regular follow-up
- 24 hour phone access
- Educational support to promote disease self-management
- Case management to ensure coordination of needed care
- Scheduling
- Transportation
- Asthma assessment of other family members
- Screening and follow up of social needs
- Mental health
- Food and housing needs
- Advocacy

Referrals for Home visits

Additional plans for the future include application to the NIH to support a program to test the effectiveness in Richmond of community based asthma interventions that have shown to be of benefit elsewhere, and participation in a collaboration of the Central Virginia Health Systems (VCU, HCA, and Bon Secours) to improve the health of children with asthma in the Richmond metro area. With community involvement and best care practices Richmond can be well on our way to losing our not-so-happy distinction of being the Asthma Capital of the United States.

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BAT CARs and BMT now at UVA: Cutting-edge immunotherapies for pediatric cancer

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Objective: The reader will be able to discuss UVA's new pediatric bone marrow transplant program and new, cutting-edge immunotherapies for pediatric cancers now available at UVA.
ACGME Competencies: *Patient Care, Practice-based Learning and Improvement and Medical Knowledge.*

For decades, children with cancer have been treated with combinations of surgery, chemotherapy, and radiation, all of which result in significant acute and chronic morbidities. Through better understanding of cancer biology and risk stratification in recent years, many children can now be cured with less exposure to toxic therapies. Still, over a third of adults who are survivors of childhood cancer suffer from at least one severe or life-threatening chronic health problem directly resulting from their therapy. While cure rates for most pediatric cancers have dramatically increased, for children with high-risk or metastatic disease or certain cancers such as Ewings sarcoma, little improvement in survival has been seen in the past few decades despite intensifying therapy. For these reasons, we need novel approaches to treating cancer.

Great strides have been made in many adult cancers with the advent of drug-based immunotherapies. Monoclonal antibodies are routinely used in the treatment of breast (trastuzumab), colon cancer (bevacizumab, cetuximab), melanoma (ipilimumab), and lymphomas (rituximab, brentuximab) to name a few. Programmed death ligand 1 (PD-L1) is a molecule often expressed by many tumors that signal through the programmed death 1 (PD-1) receptor on immune cells, preventing immune-based killing of cancer. Drugs that modulate the PD-1/PD-L1 axis and other checkpoints "unmask" the anti-tumor immune reaction and have demonstrated benefit in melanoma, non-small cell lung cancer, renal cell carcinoma, bladder cancer, and head and neck cancers. However, early-phase studies of these checkpoint inhibitors in pediatric cancer have not demonstrated efficacy.

Fortunately, a third type of immunotherapy, called adoptive cellular therapy, has recently shown incredible promise in childhood cancer. Recent advances in clinical-grade cell manipulation and culture techniques as well as genetic engineering of cells have allowed a whole new approach to attacking cancer to flourish.

T lymphocytes are a powerful tool our bodies use to fight infections and tumors. But, tumors are smart and employ many techniques to evade the immune system from detection and killing. Each T cell has a unique T cell receptor (TCR) that is specific for one particular peptide. The chances that a patient has a TCR that recognizes their tumor is miniscule. To put it into context, the most frequent group of TCRs that recognize CMV antigens occurs at a frequency of 0.03% in the body. In order to harness the power of the T cell to attack cancer, researchers have redirected millions of T cells, each with unique specificity, to one tumor antigen.

The most exciting approach redirecting T cell killing to tumors is with Chimeric Antigen Receptor (CAR) T cells. Though many tumors have been targeted, the most mature data exists with CARs directed against the B-cell antigen, CD19, expressed on pre-B cell acute lymphoblastic leukemia (ALL). Recent results have energized pediatric oncologists across the world.

Though 95% of children diagnosed with ALL will go into remission with the first cycle of chemotherapy, approximately 25% will relapse. Therapies for relapsed ALL are intensified and often include myeloablative bone marrow transplantation (BMT). Since ALL is the most common cancer in children, it accounts for the most deaths of children due to cancer.

CD19 CAR T cells have produced 70-90% complete response (CR) rates in children and young adults with multiply relapsed and/or refractory ALL. By comparison, the most recent FDA approved drugs for pediatric ALL, blinatumomab (2014) and clofarabine (2004), had CR rates of 32% and 12%, respectively, in similar patient populations.

CAR T cells is a form of personalized medicine. T lymphocytes are first collected by apheresis then genetically engineered to permanently express the CD19 CAR in a process that takes only 6 days. After appropriate quality control testing is performed, a tiny amount of autologous CD19 CAR T cells are infused to the patient over about 15 minutes. The power of this therapy comes from their capacity to proliferate exponentially in vivo with each of the daughter T cells expressing the CAR and capable of killing tumor. Responses happen rapidly with most patients in remission within 14 days of a single cell infusion.

Dr. Daniel "Trey" Lee was one of a few investigators across the US to pioneer CD19 CAR T cell therapy for children with ALL. He has now joined the faculty at the University of Virginia where he continues to enroll children and young adults on a CD19 CAR T cell Phase I/II trial (www.clinicaltrials.org #NCT02625480). He is also developing other CARs for other pediatric tumors such as medulloblastoma, ependymoma, and diffuse intrinsic pontine glioma in his laboratory in addition to leading efforts to start a pediatric BMT program at UVA.

Another approach to adoptive cellular therapy is a product called Bi-specific antibody Armed T cells, or BATs. T cells are expanded ex vivo and "loaded" with a bi-specific antibody where one end binds the T cell and the other GD2, a disialogangloside found on neuroblastoma and other tumors. These GD2 BATs are then infused in patients with cytokine (GM-CSF and IL-2) support. UVA will soon be enrolling on a multicenter Phase I/II clinical trial of these GD2 BAT cells in children with relapsed neuroblastoma and osteosarcoma (NCT02173093). Though still early in the study, responses have been seen with minimal side effects.

Bone marrow transplant was actually the first immunotherapy used to treat cancer and other diseases. Much progress has been made, especially in recent years, resulting in wider applicability and accessibility to BMT in part due to advanced techniques for alternative donors while dramatically mitigating the life-threatening complications of BMT.

Transplant options for children in Virginia have been limited in the recent past. Most patients have had to travel out of state. For a process that takes roughly 120 days, this is a huge inconvenience and sometimes an outright barrier for families who struggle to care for other children and keep jobs and insurance during this prolonged time out of state. With the advent of the new pediatric BMT program at UVA, children and parents can have this life-saving treatment without leaving the Commonwealth and our community. Families who come from outside the immediate Charlottesville area will have free or reduced-cost housing options close to the hospital during their stay. The Alyssa House which provides free housing to families

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with children undergoing these treatments is a great example of the generosity of the Charlottesville community to address the needs of these patients and others requiring a prolonged stay at UVA.

The University has made a firm and substantial commitment to bring the most cutting-edge therapies to the children of Virginia with cancer. Through our new immunotherapy programs of CAR and BAT T cells and bone marrow transplant, the best in cancer therapy has arrived in Virginia.

"How do Children of the Commonwealth of Virginia Benefit from Global Health Research?"

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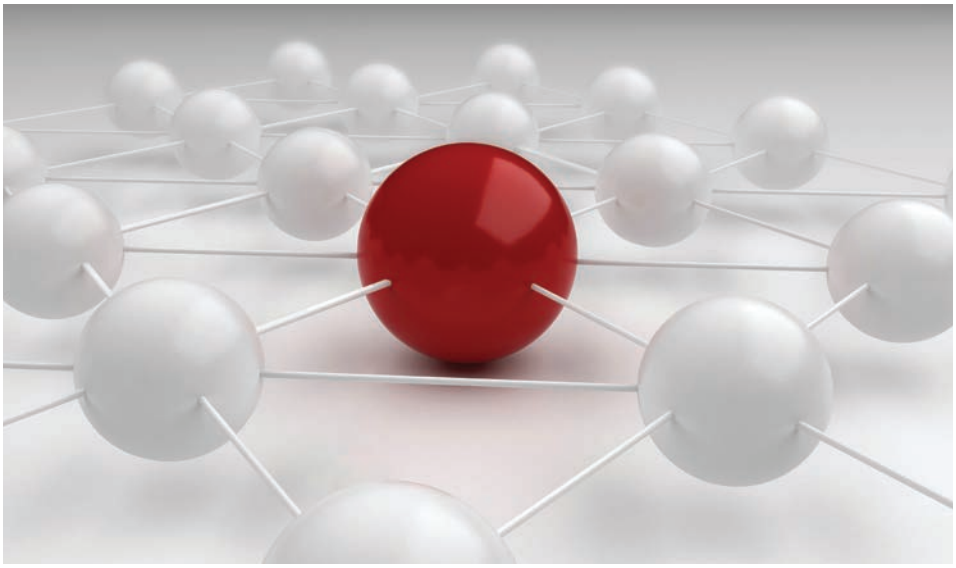
Objective: The reader will be able to identify links between key health concerns of children in the U.S. and the developing world. Learn examples of win/win U.S. global research collaborations. Discuss work at UVA on environmental enteropathy.
ACGME Competencies: *Medical Knowledge, Systems-based Practice*



We live in interesting times. Never before has there been greater recognition of the degree to which the health of all nations is interconnected, e.g., Zika, Ebola, and other emerging infectious diseases. Yet, as Americans wrestle with the costs and complexities of our own healthcare system, its commitments to leadership in global health are being questioned at the highest levels. As defined by Beaglehole and Bonita, global health is "collaborative, trans-national research and action for promoting health for all."[1] So, how do U.S. investments in global health *research* benefit Americans, and children—our most precious natural resource—in particular?

First, some background that informs how I think about that question. I am a pediatric gastroenterologist at the University of Virginia Children's Hospital whose work as a physician-scientist provides me the privilege to care for children with digestive diseases and also labor upstream on scientific discoveries to transform that care. Over the past two decades, I have partnered with leaders in the field of diarrheal diseases in Virginia, Brazil, Pakistan, and elsewhere to understand and reverse break the "vicious cycle" of childhood gut infections and undernutrition in developing countries. This work spans laboratory studies of intestinal stem cells, bacteria, and viruses; translational studies with mouse models of disease; and pediatric cohorts and trials. The sweet spot in our work is when we connect the dots between patients, diseases, and research discoveries at home and abroad.

Perhaps the most striking historical example of how global health research has benefited Virginia children is a treatment used by almost every pediatrician and parent: oral rehydration therapy (ORT). Prior to the advent of ORT, intravenous fluid therapy was the first line treatment for treatment of dehydration from diarrhea. Fundamental laboratory observations that glucose enhances intestinal absorption of sodium and water formed the scientific basis for the discovery of ORT. Captain Phillips of the US Army in 1964 first successfully tried oral glucose saline on two cholera patients in Manila. Subsequently, U.S. and international partners working in Dhaka and Calcutta contributed to the development of modern oral rehydration salt (ORS) solution. Presently, ORS is first line therapy for diarrhea-related dehydration everywhere in the world and has saved the lives of millions of children.

My UVa colleague Dr. Richard Guerrant has rightly called the development of ORT both a triumph of science and an indictment of our collective failure to extend the full benefits of medical progress and the sanitary revolution to children in the developing world.[2] Children living in global poverty who have access to ORS are now much more likely to survive diarrhea; however, because of overwhelming exposure to gut pathogens, they experience repeated bouts of diarrhea with subsequent long-term adverse effects on their growth and neurodevelopment.

In partnership with the Bill & Melinda Gates Foundation and pediatricians at Aga Khan University in Pakistan, my UVa colleague Dr. Sana Syed and I are now studying a cohort of children in Pakistan with repeated infections of the intestines who fail to grow, despite access to good nutrition and medical therapies like ORT and antibiotics. Comprehensive evaluations for children who fail to respond to nutritional interventions will include an upper gastrointestinal endoscopy to diagnose underlying illnesses and provide tissue and fluids to analyze using cutting edge approaches to assess gut gene transcription, the metabolome, and microbiome. The goal of these multiomic approaches is to understand the pathophysiology of gut damage and malabsorption in children in order to ultimately prevent and reverse this damage.

Similar approaches are being used by my GI colleagues to study digestive diseases in U.S. children, most notably inflammatory bowel disease and short gut syndrome, chronic diseases associated with significant disability and healthcare costs in the U.S. Despite access to the best care in the world and the best medicines, a sizable number Virginia children with these conditions will not meet their full growth potential. Not so different, perhaps, from the children we study in Pakistan. Although the growth and diseases of children in the developing world, at times, seems far away from the concerns of Virginians, the promise of global health research remains cures and improved therapies, like ORT, for the benefit of all.

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Competitive Sports Participation in Children and Adolescents with Heart Disease

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Objective: The reader will be able to discuss the factors that need to be considered when asked about sports participation with patients with heart disease. Describe the benefits of sports participation, the times when sports restrictions are necessary. Explain the risk of sports restriction.
ACGME Competencies: *Patient Care, Medical Knowledge and Interpersonal Communication Skills*

Disclosure statement: The authors have nothing to disclose

I. Introduction
Since outcomes for pediatric patients with heart disease have greatly improved, most patients are surviving into adulthood, feeling healthy and seeking high quality lives. Given these outcomes, patients are asking to participate in competitive sports. The American Heart Association and American College of Cardiology recently released guidelines for competitive sports participation for patients with heart disease[1]. These guidelines are well done and extensive, but individual patients are often complex and decisions should be individualized to balance the risk of participation with the known benefits of exercise and the risk of sedentary lives and obesity.

II. Why the topic of sports in heart disease is important?
This topic is important to pediatric practitioners because the stakes are high. Sudden death associated with sports participation is a terrible tragedy and there are several well-known examples of events in individuals with cardiac disease. Second, parents and children care about sports participation. Parents frequently ask whether their child will be able to participate as early as the fetal echocardiogram and the patients start requesting participation as they grow up. Third, this is a relatively new issue. Patients, who may not have been expected to survive three or four decades ago, are now surviving into late adolescent and adulthood and thus creating these new dilemmas for practitioners. Last, there are many forms of heart disease in children, so there is no "one size fits all" solution and each patient requires individual thought and attention.

III. The case for sports participation
In healthy populations sports participation can be important for a child or adolescent's psychological and physical well-being. Sports participation provides a method for children to engage in aerobic exercise and physical activity with their peer group. For patients with congenital heart disease competitive sports participation has benefits and it is likely these benefits would be seen in other forms of pediatric heart disease. For patients with congenital heart disease sports participation has been shown to correlate with improved quality of life scores, improved exercise capacity and lower body mass indexes[2,3] Sports participation has also been associated with lower neurohormone levels and increased event-free survival[4].

IV. The case for restriction
Sports restrictions are important for two reasons: to prevent a sudden cardiac death that otherwise might not have occurred and to avoid worsening the natural history of the heart disease. To determine the risk of these events one must consider the cardiac changes that occur acutely and chronically with exercise.

Acutely with exercise there are increases in cardiac output, systemic and pulmonary artery pressures, heart rate and sympathetic drive. These acute changes may or may not be concerning depending on the type of heart disease. For example, the increased heart rate and cardiac output with decreased coronary perfusion time are likely bad for patients with aortic valve stenosis, abnormal coronary arteries or hypertrophic cardiomyopathy. An increase in blood pressure would likely increase the risk of dissection in patients with Marfan's syndrome and a dilated aortic root. The increase sympathetic drive may increase the risk of a lethal arrhythmia in patients with the potential for arrhythmias or patients with cardiomyopathies. There are also certain sports and diseases that should not be paired and require restrictions (e.g. football or boxing in a patient taking anti-coagulation medications, high altitude hiking in a patient with pulmonary hypertension or certain activities for patients who are pacemaker dependent due to risk for lead damage). While acute changes are clearly bad for some forms of heart disease, there are many forms of heart disease where the impact is less clear (e.g. repaired tetralogy of Fallot, single ventricle patients, Kawasaki disease with residual coronary artery aneurysms, asymptomatic Wolff-Parkinson-White or genetically confirmed Marfan's syndrome without aortic root dilation).

The chronic cardiac changes with exercise depend on the exact type and intensity of exercise. These changes either place a "pressure load" (e.g. weight lifting or rowing) or a "volume load" (e.g. long distance running or soccer) on the heart. These chronic adaptations are typically benign in healthy athletes but when combined with heart disease they may amplify chamber dilation and hypertrophy. In general, it is unclear whether these chronic changes will alter the natural history of pediatric heart disease.

V. The problem with restriction
Restricting patients may be an "easy" decision for the practitioner when there is uncertainty but restricting patients is far from a benign recommendation and should only occur when there is good reason to restrict.

First, preventing an athlete from participation may have a profound impact on quality of life and cause psychological consequences. In a group of patients with congenital heart disease, after controlling for residual heart disease, heart disease complexity, comorbid conditions, age and gender, patients who were restricted from sports for any reason had lower physical quality of life scores compared to patients who stated they were not restricted[2]. Studies have also shown that exercise restrictions trigger psychologic difficulty similar to grief that can persist into adulthood[5,6].

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Second, restricting athletes may also provide a false sense of security. A study of patients who were restricted by their cardiologist due to an inherited arrhythmia syndrome found that patients still spent significant time performing vigorous or very vigorous activities during daily living despite the restrictions[7].

Third, while there is a risk of sudden death in patients with heart disease, it seems as though only the minority of these occur during exercise. A large study of adult patients with congenital heart disease showed that only 10% of the sudden deaths occurred with exercise. The rest of the sudden deaths occurred during rest or sleep[8]. Even in hypertrophic cardiomyopathy, in a large population, only 16% of the sudden deaths occurred during moderate or severe exertion and 84% occurred at rest or with mild activity (walking, watching television or driving a car)[9].

Fourth, by restricting patients and preventing them from participating in public activities, they may have a worse outcome if a cardiac arrest does occur. Several studies have demonstrated that survival is better if a cardiac arrest occurs in public or at a sports facility[10,11].

Lastly, restricting patients will also increase the risk of obesity, which is a well-recognized problem in patients with congenital heart disease[12] and has significant consequences if our goal is for patients to age well and obtain a normal life expectancy.

VI. What guidelines are there to assist practitioners?

Fortunately there are recent guidelines from the American Heart Association and American College of Cardiology that address patients with heart disease who want to participate in competitive sports[1]. These guidelines address a large number of congenital and acquired heart diseases, discuss a large number of sports and can be very helpful to the practitioner. Despite the massive effort by these experts, they cannot possibly address every clinical situation and the underlying scientific literature is limited so most of the guidelines are purely "expert opinion." Given these limits the guidelines are not universally followed by cardiologists or patients[2,13].

VII. Conclusion

Athletes with heart disease will pose a dilemma for practitioners. While practitioners should consult the guidelines, they should also be aware of the evidence (or lack thereof) supporting the guidelines and they should individualize recommendations for each patient. There should be thoughtful conversations with patients and families and there should be shared decision making and shared risk. I agree with the approach that is recommended in a recent article in the New England Journal of Medicine addressing shared decision making: "Let me tell you about the pros and cons of options x and y so that you can decide which one matches your priorities."[14]

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"What is New with Cerebral Palsy?"

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Objective: The reader will be able to discuss new ideas regarding diagnosis and classification of Cerebral Palsy. Describe general approach to therapies in children with Cerebral Palsy. Highlight the role of the pediatrician in diagnosis disclosure, management and support of families.
ACGME Competencies: *Patient Care, Medical Knowledge, Interpersonal Communication Skills.*

Cerebral palsy (CP) is a common disorder, and most pediatricians have experience with it in their practice. Placed in the context of intellectual disability, speech and hearing impairments, autism and ADHD, it contributes significantly to the tasks of the primary care pediatrician related to identification, diagnosis, referral, support, coordination and management. This communication aims to highlight some new ideas around classification/conceptualization, available treatments, new resources for families and professionals, and the ongoing challenge for the pediatrician to support and coordinate management of children with CP.

Overview of CP

Cerebral palsy is really a group of disorders affecting movement and posture, attributable to non-progressive disturbances to the developing brain [1]. CP is the most common cause of chronic childhood-onset physical disability, affecting 3.5 per 1000 births [2], with increased prevalence in males (3.8:3.2/1000) and non-Hispanic black children (1.5:1)[3]. No cure is available or imminent for CP. The primary pathology is an upper motor neuron disorder associated with delayed motor development, abnormal muscle tone (i.e. hypertonia, dystonia, spasticity) and weakness, loss of selective motor control, and impaired balance[4]. The primary lesion in the brain is not progressive, but the musculoskeletal consequences, which include muscle contractures and bony deformities, worsen over time[5-7].

During typical motor development, muscles grow in response to the stimulus of stretch from motor activity, which is diminished in CP. Hypertonia, particularly spasticity, initially produces dynamic contractures (muscles are of normal length but their increased tone does not allow stretch to their full length). Inadequately stretched muscles then fail to grow in proportion to growing bones, resulting over time in static contractures (short muscles)[8]. The growing skeleton constantly remodels in response to activity, which when limited or abnormal as in CP, leads to development of bony deformities[9]. Over time, interaction of spasticity, weakness, contractures and bony deformities at multiple joints affects the quality and efficiency of movement and other aspects of physical function[9]. Untreated, these are associated with pain, fatigue, and arthritis and can lead to significant lifelong impact on the lives of these children and their families.

Children with CP can have unilateral or bilateral limb involvement with a wide range in severity. The Gross Motor Functional Classification System (GMFCS) is the international standard for classifying the degree of mobility impairment in CP[4]. The GMFCS is a five-level ordinal rating system that is reliable, valid, and stable over time[4]. It has been shown to have significant prognostic utility and a major influence on treatment goals and recommendations[10]. Children in Levels IV and V, approximately 30-40% of the population, are non-weight-bearing and weight bearing with support, respectively, and both groups are non-ambulatory[11,12]. Children in Level III require external aids to walk and wheelchairs for longer distances. Children in Level II can walk unaided except when negotiating challenges such as stairs or uneven surfaces. Children in Level I can walk without aids and participate in functional activities with some difficulties. Children in these latter three groups (GMFCS I-III) are ambulatory, represent two thirds of the population of children with CP[11,12], and, as a result of their musculoskeletal impairments; experience diminished gait quality and efficiency, decreased functional activity, participation and independence, and poorer health-related quality of life. Ambulatory children with bilateral limb involvement and spasticity (spastic diplegia) are the main candidates for surgical and non-surgical interventions to improve gait function often employed in children with CP.

Impact of CP on individuals and Families

The International Classification of Functioning, Disability and Health (ICF), developed by the World Health Organization (WHO), provides a unified, standard language to describe how people with a health condition function in their daily lives[13,14] and provides a framework to conceptualize types of interventions and outcomes. A condition such as CP is associated with specific impairments (body-level problem) in "Body Structure" (e.g. brain lesion in CP, bone deformity) or "Body Function" (e.g. spasticity or reduced motion). These impairments might lead to functional limitations (individual-level problem) in "Activities" (e.g. walking) and restriction (society-level problem) of "Participation" (e.g. playing sport). Most medical treatments target impairments (e.g. lower extremity spasticity) at the level of body structure and function, with the assumption (often unmeasured) that these will achieve downstream benefits on activities, participation and overall quality of life, which is where the family goals for treatment are focused[15]. However, evidence that these treatments achieve these broader important goals remains insufficient as they have not always been measured; a recent study mapped outcome categories in 229 studies on effects of orthopedic surgery and found that only 9% of studies included outcomes on activity or participation, and only 2/229 studies assessed quality of life16. With the use of the ICF framework, and the development of specific outcome measures for activity and participation (as defined by this framework), more recent research efforts usually include aims regarding the impact of interventions on these goals (e.g. activity and participation) that are most important to

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families. Thus, in decision-making regarding potential interventions, especially surgical treatments, it is important to discuss expectations of the interventions. Will this muscle tendon lengthening and rotational osteotomy only correct the impairments of short, spastic muscles and bony deformity (body structure and body function in the ICF model) or will it also help my child walk better and participate better in peer activities (activities and participation in the ICF model)?

Role of the Pediatrician

Diagnosis

The diagnosis of CP is made clinically when children have abnormalities of muscle tone, movement and deep tendon reflexes in the context of motor delay. Although in many cases it can be straightforward, the diagnosis of cerebral palsy can be challenging. Straightforward cases are those that occur in children with identified early risk factors (e.g. extreme prematurity with high grade intraventricular hemorrhage) who present with significant motor delay and classic signs of spasticity (e.g. scissoring, toe-walking, stiffness, hyperreflexia). Challenging cases are those that are unexpected due to lack of identified early risk factors (e.g. full term infant following uneventful pregnancy and no problems at birth) who present with significant motor delays but without spasticity (e.g. predominant hypotonia, with or without tremor or ataxia). Best practice for diagnosis includes: a review of risk factors by history, neurological examination, standardized motor assessment, neuroimaging, and consideration of alternative diagnoses.[17] According to the published practice parameter18, once the clinical diagnosis is established or suspected, the primary next step is brain MRI. If the brain MRI shows evidence of vascular-pattern brain injury, then further work up for underlying coagulopathy should be considered. Further, if brain MRI shows a malformation, then genetic evaluation should be considered. This practice parameter was published in 2004, and there has been increasing evidence since that time regarding prevalence of genetic differences in CP[19,20]. Consideration for genetic testing is evolving and will play a more significant role in evaluation over the next few years, analogous to what has occurred in autism and intellectual disability. Final diagnosis of CP may require collaboration with consultants, such as physical therapists, developmental pediatricians, child neurologists, geneticists, physiatrists and orthopedists.

Once the diagnosis has been made, communicating that diagnosis to parents and family is extremely important.21 This can be difficult, and often requires multiple conversations. The primary care pediatrician plays a key role in facilitating this process by referral to appropriate consultants and following up those initial conversations as parents come to grips with the diagnosis, prognosis, and treatment options. A trusted primary pediatrician can help guide and support families through the process, which often takes time and often contains a fair amount of uncertainty, especially when the child is quite young. This discussion can and should begin even before the diagnosis is finalized. The article by Shevelle and Shevelle[21] is excellent and proposes elements for improved discussions about the diagnosis of CP. These elements include (1) the use of understandable terminology discussed plainly, (2) disclosure of information fully and honestly, (3) the frank highlighting of uncertainty, (4) open referral to relevant consultants and direct service providers and appropriate information sources (e.g., support groups, websites), (5) discussion of future realities or at least future possibilities based on available data, balanced with hope, and (8) concrete suggestions about what the family can do to support their child.[21] Again, I recommend beginning difficult discussions as early as possible, even before diagnoses are finalized. Parents usually are already worried and need to begin discussing their worries as the possibilities are investigated.

Following diagnosis, it is important to classify the type and severity of CP. Classification follows a format described by Rosenbaum and colleagues.[22] The four components of classification are motor type (including functional severity as per the GMFCS), associated conditions, anatomic distribution and neuroimaging, and etiology and timing of brain injury.[22] An example of this classification scheme applied to an individual child is as follows:

1. Spasticity in a child that can walk with a walker (GMFCS III),
2. associated with attention deficit hyperactivity disorder and strabismus, with
3. bilateral distribution of spasticity in all extremities associated with periventricular leukomalacia on MRI,
4. apparently due to complications of prematurity (26 weeks, bilateral intraventricular hemorrhage).

Classification can be useful for prognostication, development of goals, and selection of appropriate treatments. Prognosis of severity is not always reliable before age 2, but by age 4 or 5 is usually reliable[17]. An important aspect of prognosis that parents often worry about but may not ask is that the majority of children with CP have normal life expectancy with only 5-10% dying during childhood.[17] Those at highest risk for early death have severe physical impairments (no independent movement, minimal hand use, and poor head control) and, usually, associated epilepsy and intellectual disability.[17]

Treatment Referral and Coordination

Treatment of children with CP takes place in local communities and in specialized cerebral palsy centers, often associated with universities and children's hospitals. Primary care pediatricians play a key role in treatments by virtue of referral to specialized care centers

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and working in tandem with subspecialists to provide comprehensive care.

Many treatment options have been utilized in CP, sequentially and in combination, in an attempt to address specific impairments caused by the pathophysiology described above. The main intervention categories utilized in children with CP are listed below. Although each of these interventions targets different impairments, decisions of which to pursue and when, are sometimes controversial due to insufficient evidence of comparative effectiveness. Consequently, recommendations may vary considerably across centers.

Surgical Interventions

• *Selective Dorsal Rhizotomy (SDR)*: a neurosurgical procedure that selectively or proportionately sections dorsal rootlets arising from the spinal cord that carry sensory information from legs to the brain. These pathways control muscle tone and disrupting them has a direct effect on reducing spasticity. Three randomized trials have demonstrated efficacy of SDR in reducing muscle tone, increasing range of motion, and (modestly) improving gait function

• *Orthopedic Surgeries*: a) Soft tissue surgery alone: muscle-tendon lengthening; or b) Soft tissue surgery and bone surgery (corrective osteotomies). Soft tissue procedures reduce fixed contractures to improve range of motion, while rotational osteotomies correct bone deformities (realign segments) that decrease efficiency of muscles attached to these bones. There is good evidence that orthopedic surgery is effective in correcting these impairments, but less evidence on whether this leads to better mobility or gross motor function.

• *Intrathecal baclofen pump*: a neurosurgical procedure that inserts a catheter into the subarachnoid space at the lumbar level of the spine and feeds the catheter up to the thoracic level. The catheter is attached to a pump that is implanted subcutaneously over the lower abdomen. The muscle relaxant baclofen is infused into the subarachnoid space for the purpose of decreasing muscle tone (spasticity, dystonia or both).

Non-surgical Interventions

• *Botulinum toxin or phenol muscle injections in lower extremities (Neurotoxin)*. These address both spasticity in affected muscles and muscle force imbalance at a joint since these effectively weaken targeted muscles.

• *Physical therapy (PT). This addresses weakness, range of motion and function through active therapy.* This category will also include other standard conservative interventions such as braces which provide joint support or assistance during gait. The general approach to physical therapy is changing from a maintenance model of low intensity therapy over long periods of time to bouts of intense therapy over discrete periods of time (4 to 8 weeks, for example). This is driven by evidence that was started by intensive therapies in unilateral CP but is now broadening to bilateral types of CP.

• *Orthotics or bracing and adaptive equipment.* Orthotics or braces are recommended for joint support to enhance mobility and stability and to maintain range of motion; adaptive equipment is recommended to compensate for functional limitations to facilitate care and to promote as much independence as possible, particularly to foster age-appropriate social participation.

A recent review of randomized control trials (RCTs) and systematic reviews of 64 discrete interventions in CP (ambulatory and non-ambulatory) concluded that the scientific data for most interventions were limited, inconsistent, and/or insufficient to guide decision-making23, with 30-40% having no evidence to support their use, and 20% having evidence indicating that they were ineffectual and even harmful. SDR was the only surgical procedure that had sufficient high-level evidence to warrant recommendation, and this was only for the reduction of spasticity, not for improved function or self-care23. These findings were echoed in the 2010 White Paper from the Agency for Healthcare Research and Quality (AHRQ)24. This is not to say that orthopedic surgery is unwarranted, but rather that the level of evidence of the short and long-term effectiveness is still lacking. "Effectiveness" of interventions in CP must be defined ultimately by outcome measures that incorporate child and family perspectives and goals in order to be meaningful.

Support and Guidance

Deciding on specific treatment courses can be difficult for parents. Pediatricians can help through connecting parents with information and providing a safe space for discussion of treatment options. Novak's review regarding evidence based diagnosis, health care and rehabilitative treatment provides a useful guide for pediatricians and others regarding the evidence base for interventions, based on general type and severity of cerebral palsy.17

Recommended resources for patients and pediatricians

A superb resource for families of children with CP is the CP Toolkit (https://cpnowfoundation.org), developed by Michele Shusterman and colleagues of CPNOW, a non-profit organization created to support research in the area of neurorecovery and to help support families with cerebral palsy. Modeled after a similar "toolkit" developed for autism, the CP Toolkit is a collaborative effort between parents of children with cerebral palsy and care providers (physicians, surgeons, therapists, and others). Ms. Shusterman also hosts a blog called CP Daily Living, which is an excellent resource (http://cpdailyliving.com). Recent posts include information on mental health, equipment such as gait trainers, and making vehicle modifications. I have found this blog informative for my own practice, so I think it is useful to care providers as well as families. The American Academy for Cerebral Palsy and

cont. page 15...

Developmental Medicine has begun the development of Clinical Care Pathways for guidance in specific areas. A Care Pathway is a practical summary, including an algorithm, of evidence informed guidelines or the best evidence, for an aspect of care/services for individuals with childhood-onset disabilities intended to inform clinical practice. Thus far, care pathways regarding dystonia, drooling, and osteoporosis in cerebral palsy have been developed. A link to these pathways: https://www.aacpdm.org/publications/care-pathways. These can be useful to pediatricians. I also particularly recommend the references by Novak and Shevelle.[17,21]

What is available at the University of Virginia?

The cerebral palsy program at the University of Virginia (UVA) has considerable longevity and has been growing. UVA has professionals skilled in the evaluation, diagnosis, treatment, and management of children with CP. These include: orthopedics, developmental pediatrics, physical medicine and rehabilitation, physical and occupational therapy, speech therapy, nutrition, social work, psychology, neurology, medical genetics, prosthetics and orthotics, and equipment evaluation. The range of surgical options is available. Further, intensive therapy programs are available. These intensive programs may include availability for prolonged stay at nearby hotels to allow children and families to stay for 2 to 4 weeks if warranted. Currently intensive therapy is available at the University of Virginia and also at Virginia Tech/Carilion Research institute (VTCRI), with particular expertise in constraint-induced movement therapy for children with hemiplegia. UVA and VTCRI are collaborating on two R01-funded research projects related to intensive therapies for infants and children with hemiplegia. Both projects are recruiting subjects. The infant project (enrolling 6month to 2 years) randomizes children to three active treatments, two involving constraints and one involving intensive bimanual therapy. The child project (enrolling ages 2 to 8 years) randomizes children to usual care for 6 months or 4 variations of constraint (full-time full arm cast vs part-time hand/wrist splint) plus intensity (2-1/2 hours per day 3 days a week vs 3 hours per day 5 days a week) for a 4 week program. In addition to these randomized clinical trials, both UVA and VT offer clinical programs for intensive therapy for both unilateral and bilateral varieties of cerebral palsy. Clinical programs are individualized to parent and child goals. For information regarding clinical trials contact Jodi Darring at JGD7S@hscmail.mcc.virginia.edu. For information regarding clinical programs, contact UVA Patient Friendly Access at 434.924.0123.

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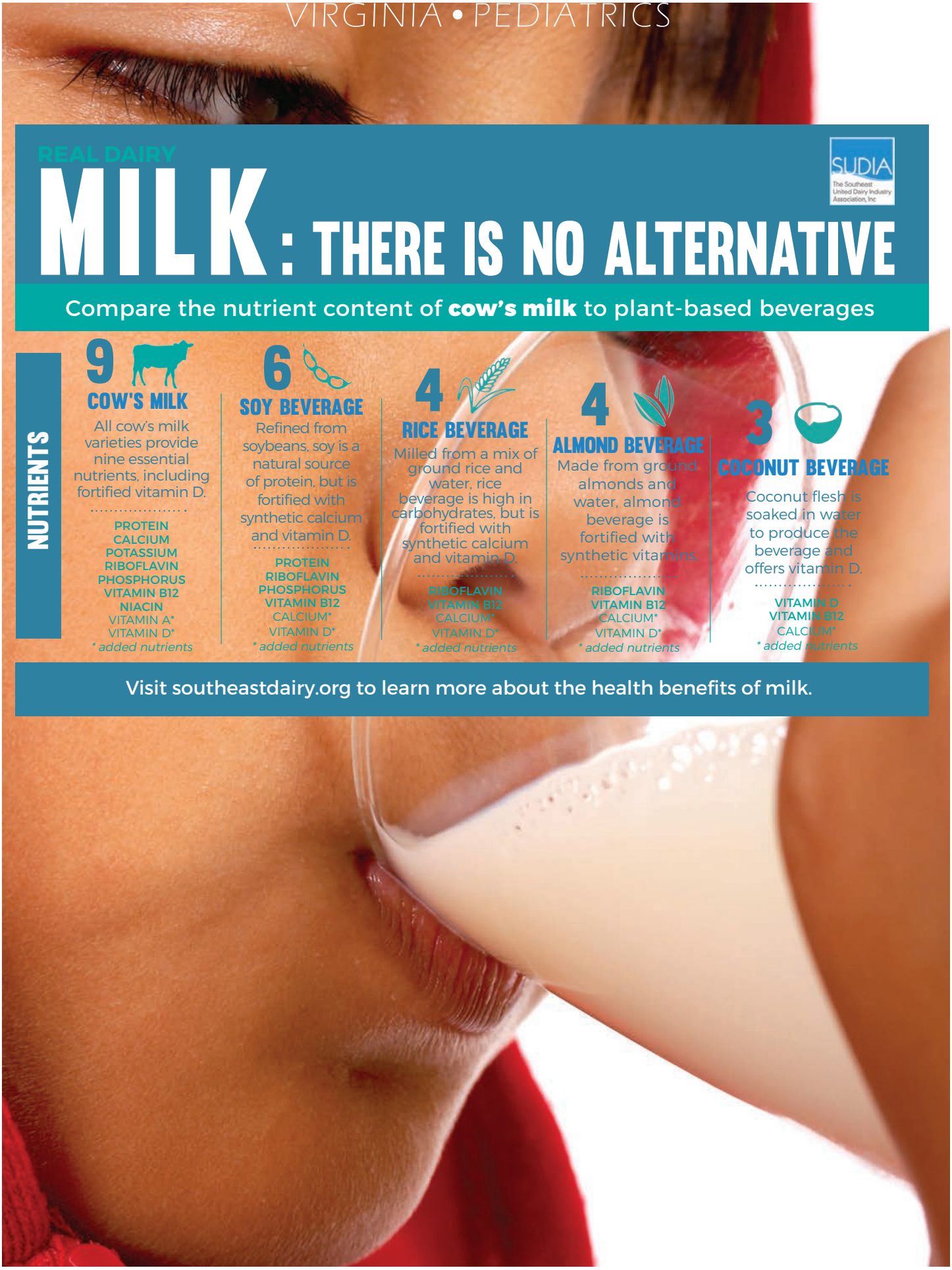


REAL DAIRY

MILK: THERE IS NO ALTERNATIVE

SUDIA
The Southeast United Dairy Industry Association, Inc

Compare the nutrient content of **cow's milk** to plant-based beverages

NUTRIENTS

9 COW'S MILK

All cow's milk varieties provide nine essential nutrients, including fortified vitamin D.

PROTEIN
CALCIUM
POTASSIUM
RIBOFLAVIN
PHOSPHORUS
VITAMIN B12
NIACIN
VITAMIN A*
VITAMIN D*
** added nutrients*

6 SOY BEVERAGE

Refined from soybeans, soy is a natural source of protein, but is fortified with synthetic calcium and vitamin D.

PROTEIN
RIBOFLAVIN
PHOSPHORUS
VITAMIN B12
CALCIUM*
VITAMIN D*
** added nutrients*

4 RICE BEVERAGE

Milled from a mix of ground rice and water, rice beverage is high in carbohydrates, but is fortified with synthetic calcium and vitamin D.

RIBOFLAVIN
VITAMIN B12
CALCIUM*
VITAMIN D*
** added nutrients*

4 ALMOND BEVERAGE

Made from ground almonds and water, almond beverage is fortified with synthetic vitamins.

RIBOFLAVIN
VITAMIN B12
CALCIUM*
VITAMIN D*
** added nutrients*

3 COCONUT BEVERAGE

Coconut flesh is soaked in water to produce the beverage and offers vitamin D.

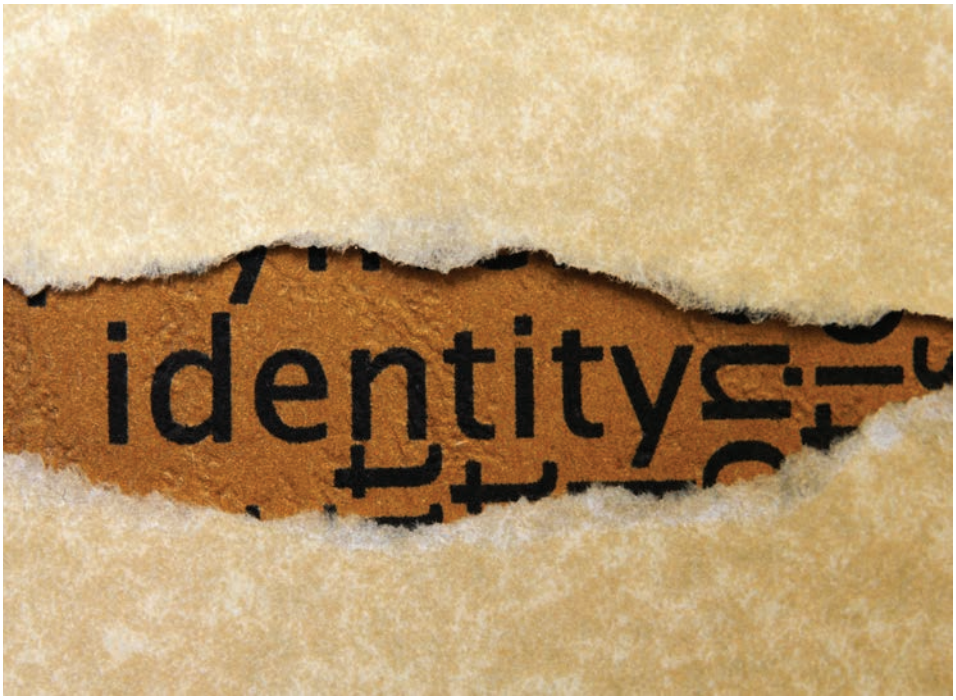
VITAMIN D
VITAMIN B12
CALCIUM*
** added nutrients*

Visit southeastdairy.org to learn more about the health benefits of milk.

5 Quick Tips for Inclusive Care for Gender Non-conforming Youth

Julia Taylor, MD, MA
Assistant Professor of Pediatrics
Department of Pediatrics,
University of Virginia

Objective: The reader will be able to identify easy ways to make their practice more inclusive for gender minorities.
ACGME Competencies: *Patient Care, Interpersonal Communication Skills, professionalism and System-based Practice.*



At UVa's TransHealth clinic (which provides comprehensive and interdisciplinary services to transgender youth), we have learned first-hand just how important positive interactions with the medical community is for the health and wellbeing of Transgender and Gender Non-conforming youth.

Significant health disparities exist for sexual and gender of minorities[1] and pediatricians can be at the forefront of providing high-quality comprehensive care for these patients[2]. Gender-expansive, Genderqueer, Non-binary, Transgender, Gender nonconforming…. While the shifting landscape of gender and sexual norms may seem confusing at times, approaching patients who identify as transgender, gender nonconforming, gender-expansive or gender queer is not. The AAP, Human Rights Campaign, and American College of Osteopathic Pediatrics have compiled guidance for pediatricians in supporting and caring for Transgender Youth[3]. Since transgender youth can present for well, sick, or subspecialty care at any time, it is important that our practices be welcoming and inclusive.

1.Ask Good Questions. Don't assume.
Name/Pronouns. Ensure that your clinic staff is asking what name your patient prefers to be called. "Hi, I'm Tim, I'll be your nurse today, what name would you like us to use today?" If the name provided does not match your EMR, make sure your staff has a way of noting the patient's preferred name (and gender pronouns). Recognize that gender identity is not always static in youth (and youth may or may not be "out") so it's ok to confirm that the information you have is still accurate at each visit.

Sexual orientation and gender identity are not synonymous. Like non-transgender people, transgender or genderqueer youth can be heterosexual, gay, bisexual, or any other sexual orientation. Encourage disclosure about sexual identity and activities by using gender-neutral terms. Instead of asking "Do you have a girlfriend?" ask "Are you dating anybody?".

2. Make Time.
If a young person brings up their gender identity or asks questions about gender fluidity, take the time to listen. This is a topic that may not be easily or quickly addressed, but if the patient has identified you as safe to talk to, acknowledge the importance of their disclosure. "Thank you for sharing that with me, it sounds like you've been thinking about this a lot. I care about all aspects of your health. What if we check in on this topic at your next visit? Can we follow-up in a few weeks/months/etc.?"

3. Ensure Confidentiality.
Providing confidential care is best practice for all adolescents, but is especially important for youth who may face discrimination, bullying, or threats of harm based upon their gender identity. Many youth may not have disclosed their gender identity to parents and relatives for fear of being rejected. Pediatricians may need to address the possibility of disclosure, but this should be carefully done and guided by the youth.

4. Answer Questions and Provide Accurate Information.
Pediatricians can provide reassurance that gender identity is frequently fluid in childhood and early adolescence. We can also acknowledge that gender identity can be uncertain and that ambiguity can be confusing for parents (and the youth), but that patience and support are important. Encourage families to practice "gender acceptance" without pressuring young people to settle on a gender.

5. Know the Resources in Your Area.
Many families may be trying to gather additional information or looking for next steps. Explore what is available in your community. Equality Virginia keeps an updated list of resources at http://www.equalityvirginia.org/resources/transgender-issues/. The Virginia Department of Health has a list of trans-friendly service providers (including mental health experts). Side By Side (formerly ROSMY) hosts LGBTQ+ youth support groups in Richmond and Charlottesville. PFLAG has local chapters and can be a great source of information and support for parents.

Also know what is available online:
- http://www.hrc.org/explore/topic/transgender-children-youth
- https://www.genderspectrum.org/
- https://www.healthychildren.org/English/ages-stages/gradeschool/Pages/Gender-Non-Conforming-Transgender-Children.aspx

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VA-AAP Newsletter Registration and Evaluation Form
(Spring 2017)

You have the opportunity to claim up to 1.25 *AMA PRA Category 1 Credit(s)* ™.

To claim CME credit, please complete the survey below, or you may also visit https://www.surveymonkey.com/r/VAAAPSpring2017 and complete online.

NAME: _____

Mailing Address: _____

E-mail Address: _____

For this activity, how many hours of CME are you claiming? _____ (Max. 1.25 hours)

As a result of reading the articles, will you make any changes in your practice? □ Yes □ No

Please list up to 3 strategies that you plan to implement as a result of reading the articles? (*answer required for credit*)

1. _____

_____

2. _____

_____

3. _____

_____

If you will <u>not</u> make any practice changes, did this activity reinforce your current practice of pediatrics? □ Yes □ No
Please explain:

How could this activity be improved?

Future Topic Requests (optional):

	Excellent		Average		Poor
Overall, how would you rate this activity?	5	4	3	2	1

This CME activity will expire on 5/1/2018.
Please send form to: CME Office, 601 Children's Lane, Norfolk, VA 23507
Please allow 4-8 weeks to receive your certificate if submitting by mail.

10 Things to Know about Keeping Virginia's Kids Healthy with the FAMIS Programs

More than 600,000 – or 32% - of Virginia's children are enrolled in Virginia's FAMIS programs (which include FAMIS and Medicaid for Children or FAMIS Plus). An additional 75,000 Virginia children are eligible for free health insurance through the FAMIS programs, but they are not enrolled.

Virginia's FAMIS programs cover routine care that all kids need to stay healthy – such as shots, annual exams, and dental and vision checkups. They also help pay for eyeglasses, filling cavities, medically-necessary orthodontia, behavioral health care and other services. Most importantly, the FAMIS programs cover hospitalizations and related expenses if the child gets sick or has an accident.

1. Children younger than 19 can qualify for the FAMIS programs, if their family meets income limits and the child is a U.S. Citizen or legal immigrant. For a family of four, the income limit is $50,430 yearly.

2. There are no monthly or yearly fees to participate in the FAMIS programs. Some families may have to pay a small co-payment ($2 or $5) for some medical services. There are no co-payments for preventive services, like well-child checks or twice-yearly dental exams.

3. Families can apply for the FAMIS programs several ways: online, by calling Cover Virginia (1-855-242-8282), by going to their local department of social services or submitting a paper application via snail mail. Specially trained outreach workers are available to help families apply in some areas of the state.

4. Families must renew their child's coverage annually. Families can renew coverage by calling Cover Virginia (1-855-242-8282), going online or returning a paper renewal application to their local department of social services in person or by mail.

5. Dependent children of state employees are eligible for the FAMIS programs if their parents meet the income guidelines.

6. Breast pumps and lactation consultation services are available to all pregnant and postpartum women enrolled in Medicaid, FAMIS or FAMIS MOMS. A woman may request a free breast pump or lactation consultation at any point during her coverage period, if she intends to breastfeed her baby, by talking with her doctor or managed care organization (MCO). Electric breast pumps will require pre-authorization by the provider. Please review this Fact Sheet for more information.

7. Children born to mothers enrolled for the FAMIS programs on the day the child is born are "deemed" to have applied and been determined to be eligible for coverage. No application or eligibility determination needs to be completed for the newborn. The mom just needs to call Cover Virginia or her local department of social services to let them know her baby was born to enroll the infant or go online to Cover Virginia.

Effective October 2016, a renewal of eligibility, rather than a new application, should be completed to determine ongoing eligibility for the child upon turning 1. This should help toddlers maintain coverage, increasing the likelihood that they will get to their recommended well-baby appointments.

8. Behavioral Therapy is now a covered benefit for children enrolled in any of the FAMIS programs. Behavioral Therapy covers services including, but not limited to, Applied Behavior Analysis (ABA).

9. The Early and Periodic Screening, Diagnostic and Treatment (EPSDT) benefit provides comprehensive and preventive health care services for children under age 21 who are enrolled in Medicaid, also called FAMIS Plus. EPSDT is key to ensuring that children and adolescents receive appropriate preventive, dental, mental health, and developmental, and specialty services. A treatment or medical need diagnosed during an EPSDT visit must be paid by Medicaid. While children enrolled in FAMIS do not get the EPSDT benefit, they do get comprehensive well-child check-ups and coverage for mental health and therapy services.

10. Important Contact Information
- Click here to find a behavioral health provider or call 800-424-4046.
- Click here to find a dentist or call 888-912-3456.
- Click here to find the formulary for the FAMIS programs.

To ensure your families and key staff have all the information they need about the FAMIS programs, you may wish to:
- Order FAMIS posters or brochures, available free of charge from Cover Virginia.
- Encourage administrative or billing staff to sign up to receive a quarterly newsletter with up-dates on the FAMIS programs.
- Suggest administrative or billing staff participate in a free SignUpNow training, held each Spring and Fall across the Commonwealth.

Did you know?

Registration for Spring 2017 workshops is open now.

Top 10 Resolutions at Annual Leadership Forum Reflect Concerns Over Immigrant Children

Resolutions to protect the children and families of immigrants marked the top three resolutions selected by AAP leaders at the Annual Leadership Forum (ALF) in March.

The resolutions called for access to legal representation for families seeking safe haven, protections for children of migrants, and response to the executive order limiting immigration and entry.

Other top 10 resolutions addressed improving mental health access for children, advocating to national leaders to stand against hate crimes and other discriminatory behavior across the country, wider availability of epinephrine supplies in schools, and evidence-based firearm policy and research.

Following are the top 10 resolutions:

- Building Access to Legal Representation for Children, Adolescents, and Families Seeking Safe Haven
- Protect Children of Migrants
- Response to Executive Order Limiting Immigration and Entry
- Improving Mental Health Access for Children
- Advocate for Epinephrine Supply in Schools to Serve Entire School Population
- Not One More Child Should Die in a Dental Chair: Remembering Caleb
- Endorsing Evidence-Based Firearm Policy and Policy-Informed Research
- Calling for Statement from National Leaders Against Hate and Discrimination
- Medication Return and Safe Disposal
- Assisting Chapters with Membership Recruitment and Retention

Karen Remley, MD, MBA, MPH, FAAP, AAP CEO/Executive Vice President was happy to see so many of these align with the current work of the AAP Board and with the Strategic Plan.

Drs. Robert Gunther, MD, AAP District IV Vice Chairperson, Sam Bartle, MD, Virginia Chapter, AAP President, Sandy Chung, MD, Virginia Chapter, AAP Vice President, Karen Remley, MD CEO/Executive Vice President and Ken Norwood, MD, Chairperson Children with Disabilities are discussing building Virginia's advocacy efforts on behalf of children and families to preserve the gains in children's health coverage.

Dates to Remember!

37th McLemore Birdsong Pediatric Conference

April 28 – 30, 2017
Omni Hotel, Charlottesville, Virginia
For more information and registration go to www.cmevillage.com

11th Annual Pediatric and Adolescent Sports Medicine Update for Primary Care

June 15, 2017
Visit www.chkd.org/CMEevents for more information

2017 Peds at the Beach Conference

July 21 – 23, 2017
Wyndham Virginia Beach Oceanfront Hotel
Virginia Beach, VA
Register Online at www.vcuhealth.org/cme/register