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• Next Issue: Winter 2018 • • Deadline for entries: 12/15/2017

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Colleen Kraft: A Voice for All Children! Virginia Chapter, AAP Past President

Polly Roberts | Associate Director of Donor, Alumni and Stewardship Communications School of Medicine Development Office



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Colleen Kraft, M'86, H'89, takes the reins as president of the American Academy of Pediatrics on Jan. 1. Earlier this year, she spoke at the 39th Annual Pediatrics at the Beach

CME conference in Virginia Beach.

If it takes a village to raise a child, then Colleen Kraft, M'86, H'89, might say it takes a pediatrician who knows that village to heal one. Spending time in the community is what opened Kraft's eyes to the daily issues and concerns facing the children and families she cared for in the office. Nothing, Kraft says, can replace the education you receive when you observe a child's everyday environment. Some of her greatest insights came during conversations at the park, visits to the local library, school nurse's office, daycare centers and church nurseries.

"Kids spend 15 minutes in the office but they live in the community," she says. "Your investment in the community is what really makes a difference."

Kraft counts herself as someone who's been on the receiving end of community investment. Growing up near Akron, Ohio, she was part of the inaugural class of Head Start in 1965. It was there that the seed to become a doctor was planted.

"One of the teachers said, 'You're so smart. You could be a doctor when you grow up,'" Kraft recalls.

She carried thoe words with her throughout her years as a student and trainee. They continued to inspire her when she embarked on a career as a pediatrician, founded the pediatric residency program at Virginia Tech Carilion School of Medicine and taught on the medical faculties of the MCV Campus and the University of Cincinnati.

She carries them with her still as she prepares to take the reins in January for a one-year term as president of the American Academy of Pediatrics.

As part of her new role, Kraft served as the keynote speaker for the 39th annual Pediatrics at the Beach conference in Virginia Beach in July. Hosted by the VCU Department of Pediatrics, the continuing medical education course regularly attracts attendees from all over the country and Canada, and sometimes as far away as Saudi Arabia. This year's 300-plus attendees marked the conference's largest turnout ever.

Kraft encouraged the gathering of physicians, nurses, medical assistants, medical students and others to be a voice for all children. "We're the advocates," she said. "We know what children need."

Whether that translates to lobbying for Medicaid funding or working to address bias and discrimination concerns, she reminded the group of another adage about children: they're always listening.

"We're in an age with a lot of talk and rhetoric," she said. "Watch what you're saying. Children are always listening and they are looking for heroes. That's where we come in." For Kraft, community involvement has no borders. She has worked at hospitals in India, researched neonatal mortality in Ghana and trained nurses in South Africa. "As pediatricians, we care about kids all over the world," she says.

In addition to working to improve children's health, Kraft also aims to improve the health of pediatricians in her role as AAP president. Finding ways to address physician burnout is critical, she says, and advances in technology and team-based care can help.

It's all about making more time in the day for patients, and spending less time on paperwork and charting. She advised conference attendees to try scheduling a follow-up appointment using telemedicine or hiring a medical assistant to room patients and serve as a scribe as ways to reclaim time that's been lost in present-day practices.

"We can't do it by ourselves but we can do it with team-based care," she says.

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It's the same team philosophy that she applies when talking to members of the community and what inspired her to co-author the book "Managing Chronic Health Conditions in Child Care and Schools," a resource guide that emphasizes how conditions from asthma to autism are best cared for through partnerships among families, health care professionals and schools.

Sharing pediatric knowledge with these partners results in an empowered community, Kraft says. And that's how to ensure families and communities, "Go to their pediatrician before Google."



President's • MESSAGE The Power of Active Listening

We all have those days when things aren't going well. You know the feeling, when you start to wonder if your work is having any meaningful impact on your patients and their families. Do my efforts make the lives of children better?

Well, the short answer is yes, you do make an impact! This began in your medical school training and you began to learn from those wonderful mentors who inspire all of us and teach us the art as well as the science of medicine.

Trusting that we do make a difference often is what keeps us going on those stress-filled days when the drudgery can make it feel otherwise. I recently heard a story about one special child and her pediatrician that underscores how our work does indeed make the world a better place -- whether we know it or not.

The story begins with Amber Pendleton, a young pediatrician in Charlottesville who mentored a young girl name Zyanha. Zy, as she was known, was in middle school. Amber and Zy hit it off from the start, doing homework, talking about school, and discussing the importance of making healthy choices in time. As time went on, Zy began opening up to her mentor, telling her more about herself and sharing her hopes and dreams.

Amber quickly recognized that Zy was very bright for her age -- not just book smart, but with a common sense that usually comes only with time and experience. Zy was very aware of her community and how it functions. She saw the good and the bad that were around her, including the underlying discomfort in her community. As an African American living in a state so steeped in slavery, the Confederacy and Jim Crow laws that kept her ancestors down, she began to recognize what this meant to her. Although times had changed – bringing some more enlightened attitudes about civil rights and equality – Zy could see there was a long way to go. Charlottesville still held onto some of the more shameful parts of its past, especially the enslavement of blacks. The city and Mr. Jefferson's University only recently celebrated the role of slaves in building both UVA and Charlottesville – and the social and economic impacts of racial discrimination were still evident to the young lady. Still can be seen and felt today. Once Zy saw this, she began to actively question not only the distant past but the immediate present.

As time went by, Zy began to open up more to Amber. She discussed not only what she wanted to do or be herself, but her vision for the world she'd like to live in when she grew up. For Zy recognized the barriers that she faced as a black American, once that could make it hard to achieve her life's goals. She worried about the limitations to what would be available and make it difficult or even impossible for her to achieve he ambitions. Despite the heavy weight of history, Amber sensed in Zy someone who was determined not to let these obstacles stop her from achieving her highest aspirations.

Soon Zy became active in working to improve her community to remove some of the barriers she saw in her path. On her list was the public display of the inequalities she saw in in a park near her house: The statue of former Confederate General Robert E. Lee.

Zy and her friends began a petition to have the statue to be removed. The rest of this story, as they say, is now part of our recent history: white supremicists marching in Charlottesville, a protester killed in counter-protests, and an inspiration to start a national conversation on race.

However one feels about the role of statues erected to celebrate the "Lost Cause" in the South, clearly this issue that has moved from the back to the front burner in the public arena. on. So what is the moral of this story about the doctor and her young friend? It can't be said that Zy's civic involvement was the direct result of Dr. Pendleton's influence. This young lady may reached the same place and felt the confidence in herself not only to speak out but also to act on what she saw as a deep injustice in her community. But it can be said that children often are not encouraged or even allowed to develop their own opinions or dreams, let alone take an action. As pediatricians it is just as important to ensure the growth of the whole child, including learning to think and even question authority (whether or not that should apply to their parents would require another entire column!). But I like to think that Dr. Amber Pendleton helped her young friend in Charlottesville.

Here's another takeaway from this story: If things are going to change for the better, like a pebble tossed into a pond, the ripples of change must start close to our own shores before they can be expected to spread into the world beyond. As pediatricians we have been entrusted by the families of our patients to provide them and their children with information and guidance to help create a healthy environment for everyone to grow.

Sometimes this might involve a medication or a procedure. But more often than not, this involves active listening and providing a safe space and sounding board.

Hearing our young patients' concerns about growing up may be the best medicine we can ever provide.



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





Present

VIRGINIA • PEDIATRICS NEWSLETTER American Academy of Pediatrics – Virginia Chapter

Continuing Medical Education

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Sleep Saves Lives

Tiffany Kimbrough, MD, FAAP Children's Hospital of Richmond at VCU

Objective: Discuss state-led efforts targeting infant unsafe sleep and infant mortality.

ACGME Competencies: Patient Care, Systems-based Practice





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The infant mortality rate in Virginia is higher than the national average. Unsafe sleep is the leading cause of death for infants in the Commonwealth ages 1 month to 12 months. In order to improve the health of our infants, we need to rethink how we are addressing unsafe sleep practices.

These statistics empowered the Department of Social Services (DSS) to partner with The Baby Box Company and leaders from across the state to combat unsafe sleep and give every infant a healthy start to life. It is crucial to change the perception around infant sleep from a multi-generational perspective in order to protect our youngest and most vulnerable.

Children's Hospital of Richmond at VCU (CHoR) is proud to be a member of the team in the fight against Sudden Infant Death Syndrome (SIDS). As partners with the state in this endeavor, we are one of 34 (and growing) baby box distribution sites in the Commonwealth. As a general pediatrician at CHoR, I have felt the indescribable sadness of caring for families who are impacted by SIDS. I hope our efforts prevent the need to grieve with even a single additional family affected by this devastating outcome.

The Baby Box is a portable sleep environment that comes free to participants from one of the distribution sites after completion of an online education module. We are partnering with VCU Medical Center and our newborn nursery to provide a baby box to every newborn at the time of discharge. Unsafe sleep touches every facet of our society and it is vital that we send the message to every parent about the importance of keeping their littles ones safe. The box is lightweight and comes with a firm mattress and fitted sheet, in addition to other resources, such as diapers and wipes that every new parent needs.

We know that changing the practices around infant safe sleep is more than just providing a place for an infant to sleep; it is about changing the culture of what is deemed to be safe versus what is "probably going to be okay." We also know that parents get the message about safe sleep habits from a myriad of resources, from their pediatricians, nurses and other healthcare professionals. But for some, this message does not resonate.

Why is that?

We believe that we have to change the way we are messaging our families. As new parents, they are inundated with information from all sides, exhausted, and trying to make sense of a new identity as a parent. With Baby Box University, a new online education module has been generated for parents and caregivers to complete prior to distribution of the Baby Box and can be found on the Baby Box University website. This module has a quiz at the end in order to check for understanding of the message being delivered, and parents receive a certificate of completion. Members of the healthcare team will also continue to reinforce this message throughout the hospital stay.

Lastly, how will we know the message sticks? CHoR is excited to be pilot a state-wide safe sleep program that includes home visits by a nurse seven days post discharge from our newborn nursery. This visit is unlike anything else currently being done to impact safe sleep. The nurse will conduct an infant safety assessment and reinforce the teaching that was done in the hospital. Working together, we believe this approach has



the potential for our state to see tremendous improvements in the outcomes for our infants.

It is crucial to know that DSS and its partners aren't just trusting their gut that this initiative will work. There is a significant research undertaking running in tandem with these efforts to determine what interventions are effective and where there's room for improvement. Data around these processes will be key to continue to improve how we as pediatricians can reach parents with important information. I hope to provide an update next year with the data around this project and state infant mortality statistics. For more information about Baby Box distribution in the state of Virginia, visit: https://www.babyboxco.com/blogs/ news/how-to-get-a-virginia-baby-box-in-three-simple-steps

For safe sleep tips, visit: www.chrichmond.org/sleep.

Instituting a "No Hit Zone" in General Academic Pediatrics

John Harrington MD^{1,2}, Lance Irons³, Sarah Wiegand DO^{1,2}, Mark Zanni MD^{1,2}, Heidi Flatin MD^{1,2} **Objective:** Explain the purpose of implementing a "No Hit Zone" and providing a safe way to talk about corporal punishment while assessing staff and resident misconceptions on spanking.

ACGME Competencies: Patient Care, Medical Knowledge, Interpersonal Communication Skills

- General Academic Pediatrics at Children's Hospital of The King's Daughters (CHKD)
- 2. Department of Pediatrics at Eastern Virginia Medical School (EVMS)
- Medical Student at Eastern Virginia Medical School (EVMS)

Acknowledgement: Elizabeth Gershoff PhD and Kelly Dauk MD for providing their support, knowledge and expertise in helping us develop our "No Hit Zone"

If a first year medical student was told not to bring coffee into a new auditorium yet did anyway, and then proceeded to spill the coffee on the new white carpet, would that classify as a reason to give them a good hard spanking? Curiously, what we would never do professionally we seem to have no problem doing to our children. In fact, in the U.S., 76% of men and 65% of women agree that "it is sometimes necessary to discipline a child with a good hard spanking".¹ The parental argument is simply that spanking works and it does not cause any lasting negative effects. Parents rationalize that spanking is not actually hitting and it doesn't classify as abuse, since they see themselves as generally warm and responsive to their child at all other times. However, the literature is clear that spanking does not make children more compliant, it is not linked with reduction in aggression or antisocial behavior, and spanking is not linked with long-term compliance or internalization of morals.²⁻⁴ The literature provides substantial evidence that spanking is linked to worse, not better, behavior in children.⁵⁻⁸ In meta-analyses, spanking was found to be associated with significantly more aggressive and antisocial behaviors, mental health problems, difficult relationships with parents, lower self-esteem, and lower academic performance.⁶ A 2003 review of child maltreatment cases in Canada determined that 75% of substantiated physical abuse cases involved intentional physical punishment related to behaviors.⁹ A similar study from North Carolina showed that parents who spank their child or who hit them with an object were three to nine times more likely to engage in abusive behaviors such as kicking, beating, burning, or shaking.¹⁰ Studies

from other countries and cultures mirror the same negative outcomes making it clear that spanking should be considered a continuum of violence against children with the same negative repercussions.¹¹⁻¹⁴

The American Professional Society on the Abuse of Children (APSAC), which is a leading national organization supporting professionals who serve children and families affected by child maltreatment, released a recent position statement.¹⁵ In the statement, the APSAC calls for the elimination of all forms of corporal punishment and physical discipline of children in all environments including in schools and at home. They define corporal punishment as "the use of physical force with the intention of causing a child to experience pain, but not injury, for the purpose of correcting or controlling the child's behavior."15 Physical force in the form of hitting is often referred to as spanking, swatting, whipping, whooping, popping, smacking, slapping, or paddling – all of which are behaviors used in the name of child discipline. The United Nations has stated that physical punishment of children is a form of violence that is inconsistent with the "Convention on the Rights of the Child". 52 countries have actually banned all physical punishment of children. (see table).

Does this evidence on spanking help to make a change in one's general pediatric practice or the environment in which you work? At several medical institutes the creation of a "No Hit Zone" has already been implemented in some format. In 2011 Kosair Children's Hospital (now known as Norton Children's Hospital) created a unique program that borrowed from other institutions and then published their findings as a blueprint for others.¹⁶ They stated that: "A No Hit Zone is an environment in which no adult shall hit a child, no adult shall hit another adult, no child shall hit an adult, and no child shall hit another child. When hitting is observed, it is everyone's responsibility to interrupt the behavior as well as communicate system policy to those present". Our journey at Children's Hospital of The King's Daughters



(CHKD) for a "No Hit Zone" was bolstered at a recent Grand Rounds lecture in Norfolk, VA, in January, 2017 by Dr. Elizabeth Gershoff. Dr. Gershoff has written extensively on corporal punishment and its negative effects and highlighted four important reasons in her talk on why a pediatric practice might want to become a "No Hit Zone".

1. It's the right thing to do: Several organizations have already published policy statements that recommend that parents not spank their children: American Academy of Pediatrics, American Academy of Child and Adolescent Psychiatry, American Professional Society on the Abuse of Children, and the National Association of Pediatric Nurse Practitioners.

2. Parent's trust their pediatrician for advice on discipline: In a study done by Taylor et al. ¹⁷, when parents were asked how likely they would be to follow discipline advice from various sources, parents ranked pediatricians only slightly behind their spouse and their own parents.

3. Spanking is an adverse childhood experience: Spanking does not promote positive child behavior. It increases negative outcomes (mental health, behaviors, and lower cognitive ability), increases the chance of physical abuse, and has the same negative outcomes across all cultures and communities.¹⁴

4. Parent-to-Child hitting occurs in medical settings: When medical staff personnel were surveyed, they were witnessing about two incidents per day of hitting.¹⁸

With the support of the non-profit organization Champions for Children: Prevent Child Abuse Hampton Roads we decided to launch our own "No Hit Zone" at General Academic Pediatrics (GAP) at CHKD. Since our office sees about 25,000 outpatient visits of mostly low-income Medicaid families and it is the only teaching clinic for all 66 pediatric residents, we thought it would be an ideal area to pilot the intervention. We initially brought together a multidisciplinary group including ... cont. from page 6

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nurses, medical assistants, residents, social workers, managers, public relations, child abuse pediatricians, medical students, and general pediatricians. We had a brief pre-survey of all the stakeholders on what their current opinions were of corporal punishment and their comfort to intervene. Our first intervention was our previously described Grand Rounds by Dr. Gershoff from the University of Texas at Austin. Signage was posted so staff could refer to the "No Hit Zone" much like one would refer to a "No Smoking" sign. We are now gathering data on our intervention and hope to share results in the near future.

The goal of the "No Hit Zone" is to have staff and residents more likely to agree that spanking is harmful to children and that they have an obligation to intervene. We then had intervention training by Dr. Kelly Dauk (Norton Children's Hospital) to empower both our staff and the residents to intervene when they witnessed; a parent hitting a child, a child hitting a parent, or a child hitting another child. Providing key phrases and techniques to de-escalate negative behavior so that they feel more comfortable intervening if hitting is observed. In addition, the over-arching goal is to communicate to parents that a child learns best when they feel safe, valued, and connected—not fearful or victimized. A calm parent who approaches as a helper instead of an enforcer will likely get better cooperation from their child. If you want to learn more about this process please go to the website www.thisisanohitzone.org.

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Mongolia (2016)	Paraguay (2016)	Slovenia (2016)	
Lithuania (2017)	Benin (2015)	Peru (2015)	
Ireland (2015)	Estonia (2014)	Nicaragua (2014)	
Andorra (2014)	Argentina (2014)	<u>Bolivia</u> (2014)	
<u>San Marino</u> (2014)	Malta (2014)	Cabo Verde (2013)	
Brazil (2014)	TFYR Macedonia (2013)	South Sudan (2011)	
Honduras (2013)	Congo, Republic of (2010)	Kenya (2010)	
Albania (2010)	Poland (2010)	Liechtenstein (2008)	
Tunisia (2010)	Republic of Moldova (2008)	Costa Rica (2008)	
Luxembourg (2008)	Spain (2007)	Venezuela (2007)	
Togo (2007)	Portugal (2007)	New Zealand (2007)	
Uruguay (2007)	<u>Greece</u> (2006)	Hungary (2005)	
Netherlands (2007)	Ukraine (2004)	Iceland (2003)	
Romania (2004)	Germany (2000)	Israel (2000)	
Turkmenistan (2002)	Croatia (1999)	Latvia (1998)	
Bulgaria (2000)	Cyprus (1994)	Austria (1989)	
Denmark (1997)	Finland (1983)	Sweden (1979)	
Norway (1987)			

52 Countries that have banned all physical punishment of children

www.virginiapediatrics.org

Summary of the updated Clinical Practice Guidelines for the care of girls with Turner Syndrome

Roopa Kanakatti Shankar, MD Assistant Professor of Pediatrics Children's Hospital of Richmond at VCU

Objective: Review the most recent clinical care guidelines that facilitate the care of girls with TS (Turner Syndrome). Review how to improve early recognition, diagnosis and referral for Turner Syndrome and associated co-morbidities.

ACGME Competencies: Patient Care, Practice-based Learning and Improvement, Medical Knowledge, Systems-based Practice.

Turner syndrome (TS) has an incidence of 1 in 2500 live born girls and is characterized by partial or complete absence of the X-chromosome. However not all girls have the classic described phenotype of short stature, neck webbing, high arched palate, widely spaced nipples, and primary ovarian failure, making the recognition of TS difficult. The care of girls with TS requires early recognition and a multidisciplinary team of specialists in genetics, endocrine, cardiology, ENT, orthopedics, ophthalmology, developmental behavioral pediatrics and psychology with a supportive primary care physician. Recently published clinical practice guidelines arise from the proceedings of the International Turner Syndrome Meeting in 2016, and are endorsed by the Pediatric Endocrine society and the European society for Pediatric endocrinology. The guidelines cover 5 different domains of TS care: 1) diagnosis and genetics 2) growth 3) cardiovascular health 4) neuropsychological issues and other comorbidities 5) transition to adult care that is summarized in this review, with a focus on the pediatric aspects of TS.

Diagnosis and Genetics

Turner Syndrome is diagnosed in phenotypic females with a peripheral blood karyotype confirming the presence of one X-chromosome and partial or complete absence of the second X-chromosome and with one or more clinical features of TS. Only 40-50% of girls with TS have classic monosomy with a 45,X karyotype. Another 15-25% of patients have a mosaic 45, X/46 XX karyotype while 5-12% have a Y-chromosome in the karyotype. Ring X and isochromosome X are other karyotypes often seen in TS. The latest guidelines recommend that patients with terminal deletion distal to Xq24 or isodicen-



tric Xq24 should not be classified as TS. The diagnosis of TS is confirmed by a peripheral blood karyotype, with at least 30 metaphase spreads analyzed which will identify 10% mosaicism with 95% confidence. Prenatal detection of fetal cystic hygroma and obstructive left sided heart lesions such as coarctation of the aorta should prompt concern for TS. An amniocentesis may be undertaken to diagnosis TS but a postnatal karyotype should always be undertaken in individuals diagnosed prenatally with TS. Non-invasive prenatal testing such as, cell-free fetal DNA in maternal blood, has a poor positive predictive value and is not useful to confirm prenatal diagnosis of TS. In childhood and adolescence, the recognition of characteristic dysmorphic features associated with TS (such as neck webbing, low posterior hairline, downslanting palpebral fissures, low set

ears), idiopathic short stature (any girl less than -2.25 SD with no other explanation for the short stature), bicuspid aortic valve or aortic stenosis, and delayed puberty should prompt a work up for TS. In young adults, short stature with early hearing loss (before age 40 years), infertility or frequent miscarriages should also prompt a karyotype analysis to rule out TS. Other cardiac and kidney abnormalities, Madelung deformity, scoliosis, chronic otitis media and non-verbal and visual-spatial abnormalities may also be noted as part of the TS phenotype and one or more of these should raise suspicion for the clinician to obtain a confirmatory test. Any signs of virilization in girls with TS should prompt additional testing for Y-chromosome material in the karyotype and if present, gonadectomy is recommended due to increased risk of gonadoblastoma.

Growth and Pubertal development

Short stature is seen in nearly all (95-100%) patients with Turner syndrome. Growth failure beginning in late infancy or early childhood is common in TS with an average adult height that is nearly 20 cm shorter than average women. Recombinant growth hormone therapy (at a dose of 0.35-0.375 mg/kg/week) has been shown to improve adult height in TS and is recommended in early childhood (4-6 years) and even sooner if there is evidence of growth failure. Hence patients with TS should be referred to a pediatric endocrinologist in early childhood for treatment with growth hormone. Informed discussion and monitoring of side effects of therapy and annual IGF-1 measurement, keeping it at no more than +2 SD is recommended. In patients with TS older than 10 years, oxandrolone may be considered as adjunctive therapy if predicted adult height is poor despite growth hormone therapy. Scoliosis is common in girls with TS and growth hormone therapy can lead to worsening of scoliosis and hence requires careful surveillance.

Spontaneous thelarche is reported in up to a third of patients with TS, especially those with mosaicism and up to 6% may attain menarche. Girls with TS and spontaneous pubarche should receive counseling about fertility preservation options. But most TS patients require hormone replacement therapy due to pubertal delay and primary ovarian insufficiency. Gonadotrophins (FSH and LH) may be monitored annually starting at age 11 and anti-Mullerian hormone (AMH) mea-

surement reflects the ovarian reserve. The current recommendation is to use transdermal estradiol (TDE) patches to provide low dose physiologic estrogen replacement starting by age 11-12 years in those with confirmed primary ovarian insufficiency. TDE is thought to be more physiological as it avoids the first pass metabolism in the liver. Dose changes are made every 3-6 months starting at a dose of 3-7 mcg/day using fractionated patches to achieve gradual pubertal changes over 2-3 years up to an adult replacement dose of up to 100 mcg/day. Supplemental progesterone is recommended when withdrawal bleeding is noted or after 2 years of unopposed estrogen therapy for endometrial protection.

Cardiovascular health

Congenital heart defects such as a bicuspid aortic valve (BAV), coarctation of the aorta (CoA), aortic stenosis and other left sided obstructive heart defects are very common in TS and require management and surveillance by a cardiologist. An echocardiogram is recommended soon after diagnosis in TS to evaluate for these defects. Other less common abnormalities include aberrant right subclavian artery, partial anomalous pulmonary venous connection, atrial and ventricular septal defects but may not always be detected on an echocardiogram. Hence it has been recommended to obtain cardiac magnetic resonance imaging (CMR) in girls with TS as soon as feasible without the need for general anesthesia. A routine electrocardiogram (EKG) is also recommended at diagnosis to detect conduction defects. Girls with TS are at significantly increased risk of aortic dissection in young adulthood compared to the incidence in the general population with very high morbidity and mortality. Hence the latest guidelines expand on the importance of monitoring the aortic root diameter, especially in those with a BAV or history of CoA. Annual surveillance with an echocardiogram or CMR is recommended in those >16 years with an aortic size index of 2-2.3cm/m2 by a cardiologist with adequate assessment and treatment of hypertension.

Neuropsychological Issues

Visual-spatial skills, mathematics and reading comprehension, problems with executive functioning and working memory, are commonly seen in TS. Intellectual disability is uncommon, but can be seen more frequently in those with a ring X karyotype. Autism spectrum

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disorders and attention deficit hyperactivity disorders (ADHD) may also be seen in this population. Recognition of specific challenges with the help of psycho-educational testing and remediation with classroom modification. an individualized education plan, as well as medication for ADHD, etc., can significantly improve academic achievement in TS. Hence formal neuropsychological testing at preschool, school entry and start of high school has been recommended in the latest guidelines. Inclusion of a psychologist in the multidisciplinary care for girls with TS will enhance care and also help early recognition of social anxiety and depression common in these children.

Other co-morbidities

Horseshoe kidney and duplication of renal pelvis or ureters may be seen in 10-15% patients with TS and hence a kidney ultrasound is recommended at diagnosis. Skeletal issues such as cubitus valgus, genu valgum, scoliosis, Madelung deformity, short 4th metacarpals may be seen in up to a third of patients with TS and requires a thorough assessment in childhood (5-6 years) and again in adolescence (12-14 years) with careful clinical screening for scoliosis every 6 months and referral to an orthopedic specialist if necessary. Metabolic syndrome and autoimmune conditions, such as celiac disease, inflammatory bowel disease and Hashimoto thyroiditis, are also more common in TS and the recommended screening guidelines are summarized in Table 1. Audiology screening starting at 9-12 months of age and repeated very 5 years is recommended due to the increased incidence of early onset sensorineural hearing loss in TS. Frequent ear infections and chronic otitis media will need prompt recognition and treatment by the primary clinician and referral to an otolaryngologist for consideration of placement of myringotomy tubes. Ptosis, strabismus and refractory errors are also common and an eye examination should be done at 12-18 months or at diagnosis and annually thereafter. Multiple melanocytic nevi are also a common feature of TS and while the risk of melanoma in this population is unclear, a skin examination is recommended at diagnosis and annually thereafter.

Transition to Adult Care

Young women with TS are at high risk for cardiovascular and psychosocial issues and require continued surveillance as well as ÷

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adequate hormone replacement therapy. The new guidelines recognize the critical importance of a structured transition program with core elements of assessment of transition readiness, transfer summary and self-assessment tool kit to enable young adult women with TS to continue to receive optimal care. A TS-specific transition tool kit endorsed by the Endocrine society, Hormone Health Network and TS society of the US may be found in the American College of Physicians Pediatric to Adult Care Transitions toolkit: https://www.acponline.org/system/files/documents/ clinical_information/high_value_care/clinician_resources/pediatric_adult_care_transitions/endo_turner/endo_ts_transition_tools.pdf. Peer to peer support networks and TS advocacy groups are encouraged to help enhance the knowledge and resources available to these families.

The clinical care guidelines provide the primary care physician with a framework for early diagnosis, and screening for comorbidities and serve as a tool to facilitate the recognition of the wide spectrum of physical, physiological and psychological challenges faced by girls with TS. Timely detection, and management of these comorbidities, and a multidisciplinary team approach with structured transition to adulthood will optimize the medical and psychosocial care for these young girls.

Comorbidities		Recommended Screening			
	Obesity, metabolic syndrome, and diabetes	Weight/BMI annually Blood pressure at diagnosis and every visit Lipids annually in adulthood if cardiovascular risk factors Hemoglobin A1c and plasma fasting glucose annually after age 10 years			
	Autoimmune thyroiditis	TSH and free T4 at diagnosis and annually thereafter			
	Transaminitis/steatosis/cirrhosis	ALT, AST, GGT, Alkaline phosphatase annually after age 10 years			
	Celiac disease	Transglutaminase antibodies for celiac screen at 2-3 years of age and every 2 years thereafter			
	Cardiovascular abnormalities	TTE, resting EKG at diagnosis TTE/CMR surveillance based on risk factors Blood pressure at diagnosis and every visit Lipids annually in adulthood if cardiovascular risk factors			
	Renal anomalies	Renal ultrasound at diagnosis			
	Scoliosis and other orthopedic problems	Assess for orthopedic problems at age 5-6 years and at 12-14 years Clinical exam for scoliosis every 6-12 months			
	Osteoporosis and vitamin D deficiency	25-hydroxy vitamin D at age 9-11 years and every 2-3 years thereafter DXA scans to monitor bone mineral density on adult estrogen replacement therapy every 5 years			
	Hearing loss and otitis media	Audiology evaluation at age 9-12 months and every 5 years thereafter			
	Ptosis and vision problems	Ophthalmology exam at 12-18 months and annually thereafter			
	Dental issues	Dental and orthodontic evaluation at diagnosis and annually thereafter			

Table 1: Recommended Screening for common comorbidities in Turner syndrome

"At the Children's Hospital of Richmond at VCU, the Multidisciplinary Turner Syndrome Clinic with cardiology, gynecology and endocrine specialists, aims to provide the comprehensive medical care detailed in these guidelines to our patients with TS and, we are striving to develop a network of specialist referrals and encourage peer support groups to enhance the overall well being of these individuals."

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Spasticity and its Surgical Treatment

Ann M. Ritter, MD

Associate Professor, Pediatric Neurosurgery Department of Neurosurgery Virginia Commonwealth University

Objective: Identify patients with spasticity that maybe candidates for surgical management. Distinguish which surgical treatment may be a better option for a patient with spasticity. Illustrate the possible pathway for spasticity.

ACGME Competencies: Patient Care, Medical Knowledge

RG is a 4 year old female who was born at 26 weeks and sustaining a Grade III intraventricular hemorrhage. She has 4/5strength in her lower extremities, but mom states that her scissoring gait and toe walking have gotten worse. Her PE teachers are concerned that her tightness may be hindering her progress. She carries a diagnosis of spastic diplegia and cerebral palsy.

GR is an 8 year old female born at 26 weeks of gestation sustaining a Grade III intraventricular hemorrhage. She is in a wheelchair most of the day at school. She is non-ambulatory. Her caregivers and teachers say that activities of daily living (ADLs) are getting harder to do with her. The scissoring of the legs with diaper changes is so bad they cannot clean the diaper area well. She carries a diagnosis of spastic quadriplegia and cerebral palsy.

What do these very different patients have in common?

The patients may both potentially experience improvement in spasticity with surgical intervention.

Brain injury is a common cause of spasticity in the pediatric population ⁽¹⁾. The inhibitory pathways from the brain that control the number of signals that stimulate the motor neurons are decreased in this condition. This allows an unchecked number of stimuli to the muscle leading to spasticity (Figure 1, above). Spasticity is defined as a restriction or "catch" to movement that is dependent on velocity. It is described by the number of limbs affected and the treatment is based on that number.

Treatment of spasticity can include medications such as baclofen or Zanaflex, or



injection such as botox (botulinum toxin). However, surgery offers long term benefit for many patients ⁽²⁾. Our first patient is diagnosed with spastic diplegia because she has good strength in her lower extremities but normal movement is hindered by spasticity. She is able to get up from a sitting or crouching position, is functional and can participate in physical therapy. This patient is a good candidate for a selective dorsal rhizotomy (SDR). A minimally invasive approach through a single laminectomy at the level of the conus has minimal complications and shorter hospital course ⁽³⁾. The SDR involves removing a portion of the sensory input while the patient is under general anesthesia. Using intraoperative electrophysiological monitoring, each nerve root is divided into rootlets. Rootlets are graded based on their response within the muscle group or its spread to adjacent muscles. Nerve fascicles that stimulate distal muscle groups or the opposite side are resected with no greater than 75% of the total root removed (Figure 2 on page 12). This procedure requires intense PT after surgery to regain strength. The outcomes in properly chosen patients are excellent. Gross motor scores and functional scores are permanently improved for years after the procedure ⁽⁴⁾. Patients do not require lifetime follow up besides normal visits for spasticity and other CP related issues.

Our second patient with spastic quadriplegia is a candidate for SDR as well, but baclofen pumps are another option in this case ^(5,6). Baclofen acts as the inhibitory signal by interfering with the release of excitatory transmitter at the interneuron in the anterior horn. A baclofen pump requires placement of an intrathecal catheter into the CSF space and baclofen is pumped directly into the CSF space. The catheter is connected to a reservoir that is placed subcutaneously in the **Figure 1:** The lack of brain inhibition on the interneuron in the spinal cord is believed to be the cause of spasticity.

right or left lower quadrant of the abdomen (Figure 3 on page 12). A computer is able to program the pump through the skin to deliver the correct amount of medication. The pump requires maintenance to include medication refill and visits to the MD to slowly increase the medication dose. Medication withdrawals can occur and patient selection is based on spasticity and likelihood that family will follow up⁽⁷⁾.

Mild spasticity can be treated with long term medications. Spastic diplegia can be treated with an SDR. Spastic quadriplegia can be treated with a SDR or baclofen pump. The initial and long term management of these patients is best implemented through a multidisciplinary team approach, assistance from physical therapy as well as family commitment.

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Figure 2. Artist account of stimulation of fascicles and resecting in a SDR.



The selective dorsal rhizotomy procedure is an operation used to improve spasticity (muscle stiffness) in cerebral palsy. The surgery, pioneered in the US, involves cutting some of the sensory nerve in the lower spine. It is suitable for children between the ages of 3 and 12 and the operation can take 4-5 hours.



Figure 3. The placement of baclofen pump into subcutaneous pocket and catheter into spinal space.

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"Rx for Food": One healthcare solution to "Food Insecurity"



Burke Pediatrics, LLC has completed a pilot project screening its patient population for food insecurity. It developed a partnership with "Food for Others", a local food pantry serving food to those in need in Northern Virginia. 58,000 of the 180,000 Fairfax County school children received 1, 2 or 3 meals per day at school. Families identified as food insecure by a self-administered, nationally standardized, 2 question questionnaires were given a "prescription for food" that could be filled at the "Food for Others" food pantry. Participants received a special allotment of emergency food weekly for 8 weeks during the summer school recess. 8.6% of the 2000 patients screened were identified as "food insecure." Somewhat surprisingly, 25% of the identified food insecure families were commercially insured; as anticipated 75% were insured by Medicaid. 7,600 pounds of food were dispensed to 42 families (333 total individuals were served during the 2017 school year summer recess). 35 of the 42 families served through the "RX for Food" pilot program had not previously accessed food at this food resource.

Burke Pediatrics LLC is initiating a recruitment effort to engage the primary care practices of Fairfax County in screening all patients for food insecurity and connecting those <u>screening positive</u> with available food resources. In addition to the *Toolkit for Pediatricians* mentioned below, Burke Pediatrics is offering to provide the materials used in their implementation pilot program, "RX for Food." and guidance to medical practices interested in screening for "food insecurity".

Capital Area Food Bank and its 13 food pantry partners in Fairfax County that are part of the USDA food program will provide these commodities to qualifying households 1x per month, and can provide other emergency food as well. **Patient families of participating primary** care practices presenting a "prescription" for food (RX for Food), signed by a Virginia licensed practicing physician, nurse practitioner or physician assistant, can present this "prescription" at any of the 13 participating USDA pantries throughout Fairfax County. They will receive an up to 8 additional weekly allotments of food during the months of July and August when school is not in session.



Please call Burke Pediatrics, LLC (Dr. Garner or NP's Bennett or Lalonde) at 703-978-8855 or email: fgarner@verizon. net to get more information about our "Rx for Food" program. There is no charge. The only cost is the time necessary to review a 2-question questionnaire and write a prescription for "food."



Educate and Train Staff

Educate and train staff and leadership on food insecurity and the importance of universal screening.



Schedule Regular Screenings

Follow AAP's recommendation of screening at "scheduled health maintenance visits or sooner, if indicated."



3

Add Screening to Workflow

Incorporate food insecurity screening into the institutional workflow so it is sustainable, such as adding a screening tool into existing registration or intake procedures, or into the electronic health record.



Show Sensitivity When Screening

Learn how to address food insecurity in a sensitive manner (e.g., screen all patients to minimize stigma, normalize the screening tool questions).



References:

- 1. Rxforfood.com
- 2. Burkepediatricsllc.com (open the Nutrition tab at the top)
- 3. Foodforothers.org
- 4. Capitalareafoodbank.org
- 5. Addressing Food Insecurity: Toolkit for Pediatricians developed by AAP
- 6. F.R.A.C (http://www.frac.org/aaptoolkit)

PLANNING AHEAD

38th McLemore Birdsong Pediatric Conference March 9 – 11, 2018 Omni Homestead Hot Spring, Virginia

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SPECIAL ACHIEVEMENT AWARDS

Special Achievement awards were given during the July District IV Meeting in Denver, Colorado to:

Kristina Powell, MD, FAAP, for heading and directing the HPV Quality Improvement project.

Barbara Kahler, MD, FAAP, for encouraging and securing project grants during her presidency; developed and reconnected with state agencies with the Bright Futures Quality Improvement.



Sandy Chung, MD, FAAP, for leadership with the state medical society and directing the Telemedicine Project (*pictured to the left*).

Judicious Use of Antibiotics CQN Project

The Chapter Quality Network (CQN) Antibiotics Project is an exciting program through which the Virginia Chapter has led a QI learning collaborative amongst 6 practices to improve antibiotic prescribing and communication strategies.

The Global aim of the project is to use this project on improving antibiotic prescribing as an opportunity to (further) develop a sustainable QI infrastructure and support ongoing improvements in our practice. The CQN Antibiotics Project offered both the physician and the practice an unparalleled opportunity to improve care for children with the support of the Virginia Chapter and the AAP's expert faculty.

After the Virginia Chapter completed Phase 1 of the Antibiotic Project they were given the opportunity to continue into Phase 2 which will focus on improving antibiotic prescribing for pharyngitis and sinusitis. There will be 14 practices participating in Phase 2 of the CQN Project.

There were two Face to Face Learning Collaboratives which provided the practice leaders a clear understanding of the procedures needed to educate their practice team to start off the QI project.

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Virginia Child Advocate Award for 2017

The Virginia Chapter of the AAP annually recognizes an individual in our Commonwealth who stands up for the rights, values, and recognition of Virginia's children. This year the Virginia Child Advocate Award went to Delegate Todd Pillion. As a pediatric dentist, his expertise and experience of caring for children is invaluable in the General Assembly. In addition, his passion and determination to pass the "No Smoking in Cars" bill was unmatched. Delegate Pillion has continued to advocate for the most vulnerable by standing up for babies born with Neonatal Abstinence Syndrome and their mothers who suffer from Opioid addictions. Delegate Pillion's advocacy has been an asset to Virginia!

Sam Bartle, MD, FAAP, VA-AAP President presented the Virginia Child Advocate Award to Delegate Pillion at the Mohsen Ziai Pediatric Conference on Saturday, November 4th.

