VIRGINIA • PEDIATRICS American Academy of Pediatrics • Virginia Chapter

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American Academy of Pediatrics dedicated to the health of all children\*

We welcome your opinions and ideas.

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Jane Chappell: Executive Director 2821 Emerywood Pkwy | Suite 200 Richmond, VA 23294

Phone: (804) 622-8135
Fax: (804) 788-9987
email: jchappell@ramdocs.org
www.virginiapediatrics.org

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The 2018 AAP Leadership Fly-In, took place Monday, April 9 &10 in Washington, DC. The AAP
 and the Virginia Chapter realizes that as we enter an election year and face new challenges and opportunities to advocate for children, we all must continue to position ourselves as the top voice
 for children in the nation's capital as well as state legislatures. There could not be a more important
 time for pediatricians to be speaking up for children!



Virginia Delegation who participated in the AAP Legislative Conference/Leadership Fly-in were Drs. Sam Bartle, Barbara Boardman, Sandy Chung, Shahida Chowdhury, Micheal Donnelly, McLean Ellis, Andrea Hahn, Nadir Ijaz, Bill Moskowitz, Andrew Nuibe, Arshia Qaadir, Gauri Raval, Patricia Seo-Mayer and Wendy Schofer.



IFly-In group inside Tim Kaine's office

## President's • MESSAGE Sam Bartle, MD, FAAP President Virginia Chapter, American Academy of Pediatrics

There are many firsts in a child's life. Some are the ones we look forward to with excitement, such as a baby's first words and steps. Then there those firsts in a child's life – like the first day in school -- that we know are part of growing up, but for a parent are often bittersweet.

Such benchmark moments continue as our children demonstrate growth and maturity -- falling down while learning to walk, for example, or for older kids, the not-so-good choice to avoid doing homework.

Then there are the questions that our children are expected to ask as they grow: Why is the sky blue? Will you let me drive? We come to expect that children do or say certain things depending on how old they are.

Unfortunately, a new, more difficult question became part of the parent-child conversation in 2018: Is it safe to go to school? Will someone shoot at me? This is not one of the "firsts" we ever would imagine happening. Yet the tragic recent events have left many young people expressed deep fears, real or imagined, against gun violence.

As pediatricians, we have seen the impact that gun violence has on a child both directly and indirectly. The statistics of the number of those killed or injured in gun- related events have been known for sometime. It is known that having a gun in the home increases the chance of a fatal suicide. The news of an accidental shootings from a supposedly hidden gun has become a common occurrence; it is no longer surprising to hear about it. Sadly, gun violence has become numbingly commonplace. It is just another shooting. Nothing newsworthy there.

Our current lexicon has been sadly expanded with a drumbeat of names such as Aurora, Sandy Hook, Columbine, Fort Hood, Orlando, Las Vegas, San Bernardino, Sutherland Spring, Charleston, Marjory Stoneman Douglas High School and, so much closer to home, Virginia Tech.

Of course we shouldn't be numb to this drumbeat of names or to the lesser-known shootings that occur each day across the United States. Such acts of violence are no less disruptive to the parents, families, friends and, yes, physicians, involved.

So what's different now? In my view, the shooting at Marjory Stoneman Douglas High shootings seems to have sparked something in the same children who are expressing their fears of being shot – and has led parents and other adults to listen more closely and even speak out themselves. Having children get involved in a struggle over a social crisis is not unprecedented. In May, 1963, African-American students of Birmingham, Alabama joined the fight against segregation in the Children's Crusade. Imagine if the students of today -- like those in Birmingham 55 years ago-- , help raise the necessary awareness to the gun violence problem. Think how this could finally shake us out of our national lethargy to finally take meaningful actions to mitigate, if not totally solve, this deadly and vexing problem.

In recent months, addressing gun safety and trying to control the violence has become a priority of the AAP. Leaders throughout the organization met in Washington D.C. recently to discuss what can be done. The members attending the gathering met with their state senators and congressman to propose three recommendations: 1) raise the age to purchase a gun to 21 years old; 2) ban assault rifles; and 3) fund CDC research in gun safety (shamefully, this was banned by Congress).

Clearly, these are just first steps – just like those of the children we know and love. But to paraphrase the British philosopher Edmund Burke, "All that is necessary for the triumph of evil is that good men (and women) do nothing."

It is time to step up to the problem and let children be children and not have to worry or fear for their safety.



## KidsMD Political Action Committee (KidsMD PAC)

William "Biff" Rees, MD, MBA, FAAP | VA-AAP Chairman, KidsPacMD



When you become a Virginia Chapter member, you are ensuring a bright future for the association, but more importantly you are ensuring that the health and safety of the children of the Commonwealth and the practice of Pediatrics will be robustly defended, supported, and enhanced.

**KIDSMD PAC** The Board of Directors of the Virginia Chapter, American Academy of Pediatrics has established a KidsMD Political Action Committee (KidsMD PAC), to make contributions to key state legislators and statewide candidates and attend events that provide opportunities for pediatricians and our lobbyist to build relationships with legislators and their staff. Our political activity to date has allowed us to build strong relationships in the legislature and our new KidsMD PAC will further increase our access to legislators. This year will be more critical than ever with nineteen new Delegates just finishing their very first legislative session! We need to meet them and introduce VA AAP to them as an expert and a resource!

The healthcare debate is far from over, and we need the resources to ensure that when major decisions regarding the future of healthcare are made, especially the future of Medicaid, the voice of pediatricians is heard. This will be exceedingly critical this year as Congress struggles with healthcare and all of their actions have a direct impact on Virginia's Medicaid program, the care of children and access to health insurance.

We have a strong record of success in the Virginia General Assembly: fighting against scope of practice expansion by nurse practitioners and naturopaths; mandating child safety caps on liquid nicotine that is used in e-cigarettes; prohibiting smoking in cars with children aged eight and younger; requiring neonatal abstinence syndrome to be added to the list of reportable diseases; continuing to defeat bills that would make the sale of raw milk legal; requiring the newborn screening of critical congenital heart disease (CCHD) in all Virginia hospitals; working to protect physicians who write standing orders for epi pens in schools are just a few of the laws we have worked on in the last three years.

It costs money to advocate for pediatric providers and for optimal child health care and safety at the General Assembly. And don't think for a moment if you are a subspecialist, an academic, a hospitalist, a surgeon, a dentist or a nurse practitioner that the members of the Chapter and Board, who volunteer their time and energy, are not working for you - member or not.

We cannot continue the strong advocacy for pediatricians and our patients that we have developed without your financial support. Turning to ask practices to contribute to KidsMD PAC is critical to our success. We are asking for help from pediatric practices across the state and would appreciate your annual contribution.

Please discuss a group contribution with your practice members, either individually or at your next practice meeting. Contributing as a group is a relatively painless way to support the PAC and sets an excellent example for others to follow. <u>Please consider a practice-wide</u> <u>contribution</u> of \$500, \$250 or even just \$100 per member of your group to support the PAC as we strive to support your interests before the General Assembly.

Contributions may be made by check and mailed to KidsMD PAC, 118 N. 8th Street, Richmond, Virginia 23219. Help make our organization one that defends and protects children and promotes the practice of pediatrics in Virginia.

If you have questions, feel free to contact me by email at wcrees@gmail.com or contact the Chapter lobbyist, Aimee Perron Seibert, at 804.647.3140 or aimee@commonwealthstrategy.net



Present

## VIRGINIA • PEDIATRICS NEWSLETTER American Academy of Pediatrics – Virginia Chapter

#### **Continuing Medical Education**

This activity has been planned and implemented in accordance with the Essential Areas and policies of Medical Society of Virginia through the joint sponsorship of Children's Hospital of The King's Daughters and the American Academy of Pediatrics – Virginia Chapter.

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C. W. Gowen, Jr., MD Professor of Pediatrics, Eastern Virginia Medical School EVMS Foundation Director Chairman, Department of Pediatrics, EVMS Senior Vice-President for Academic Affairs, CHKD

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## How to Obtain Credit:

Review the articles on pages 5-13 Complete the attached VA-AAP Newsletter Registration and Evaluation Form on page 14 and return to the Children's Hospital of The King's Daughters, CME Office, 601 Children's Lane, Norfolk, VA 23507. You may also visit https://www.surveymon-key.com/R/VAAAPspring2018 and complete online. Please allow up to 8 weeks to receive your certificate if submitting by mail.

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> Michael A. McCulloch, MD Davi Michael Mendoza, MD, MS

David R. Repaske, PhD, MD Ina Stephens, MD

The CME committee members and content director have disclosed that neither they nor their spouses or partners have an affiliation with any corporate organization that may or may not have an interest in the subject matters of this CME activity.

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## Michael Mendoza, MD, MS | Medical Director | UVA Pediatric Liver Transplant Program

Objective: The reader will be able to explain the difference between unconjugated (indirect) and conjugated (direct) hyperbilirubinemia. Recall biliary atresia is the most common cause of neonatal cholestasis. Review the identification and initial evaluation of neonatal cholestasis, including when to refer to a pediatric liver transplant center. ACGME Competencies: Patient Care, Medical Knowledge

#### Background

Early detection of neonatal cholestasis, characterized by an elevation in conjugated bilirubin, is critically important. This contrasts with more common causes of jaundice, such as physiologic and breastmilk jaundice, which are characterized by elevations in serum unconjugated bilirubin.

While up to 65% of newborns develop visible jaundice in the first week of life, cholestatic jaundice occurs in about 1 in 2500 live births1. Although it occurs less frequently, distinguishing between cholestatic and noncholestatic jaundice is critical, as early detection leads to improved outcomes. The most common etiology of cholestatic jaundice in infants is biliary atresia (BA), accounting for up to one-third of all cases. Other common causes include idiopathic neonatal hepatitis, alpha-1 antitrypsin deficiency, and metabolic disorders. Of these, biliary atresia is the most common cause of death from liver disease and referral for pediatric liver transplantation.

#### **Biliary atresia**

Biliary atresia is the most common cause of neonatal cholestasis. It occurs in approximately 1 in 10,000 to 19,000 infants, depending on geographic location2. The specific cause is unknown.

Two types exist – extrahepatic "classical" BA and biliary atresia with splenic malformation (BASM), which is associated with other congenital anomalies such as situs inversus, polysplenia/asplenia, and malrotation. Any infant presenting with acholic stools should raise suspicion for biliary obstruction, with BA being the most likely cause. Prompt identification and evaluation is vital, as progression to cirrhosis, portal hypertension, end-stage liver disease and death is almost universal by age two. Additionally, prompt recognition and diagnosis allow for timely intervention with Kasai portoenterostomy. Survival with native liver is best if Kasai is performed before 45 to 60 days of life3. Ultimately, up to 70% of patients will need a liver transplant by age twenty.

## Identification and initial evaluation of neonatal cholestasis

Even if an infant is well-appearing, jaundice should be investigated if occurring early (less than 24 hours of life), prolonged for greater than 14 days of life, or is at a very high level. Among the easiest signs of infant jaundice is scleral icterus, which is usually clinically evident at levels exceeding 2.5-3 mg/dL of total bilirubin. In addition to a conjugated hyperbilirubinemia, other clues suggestive of cholestasis include acholic stools, dark urine, hepatosplenomegaly, or ascites.

Due to its wide availability, bilirubin fractionation (total and conjugated) is the most clinically useful first step in identifying neonatal cholestasis. A conjugated bilirubin >1.0 mg/ dL or >15% of total bilirubin is abdnormal and always warrants further evaluation.

Other evaluation should include measurement of serum transaminases (AST and ALT) to evaluate for hepatocellular injury, gammy glutamyl transferase (GGT) to evaluate for evidence of biliary obstruction, and protime/ international normalized ration (PT/INR) plus albumin to document any synthetic dysfunction. Initial imaging should also include an abdominal ultrasound, which may identify a congenital structural abnormality, such as choledochal cysts or the presence/absence of the gallbladder. A doppler of the portal venous system allows screening for vascular abnormalities and evidence of portal hypertension (ie splenomegaly).

Due to improved outcomes with early identification and subsequent Kasai, initial steps focus heavily on excluding biliary atresia. Details from history, however, may suggest other etiologies of neonatal cholestasis. One should ask about history maternal or neonatal infection, prior history of ABO or Rh disease (hemolysis), delayed passage of meconium (cystic fibrosis, hypothyroidism), newborn screen results (galactosemia), and other siblings with a history of cholestasis as infants (Alagille's, progressive familial intrahepatic cholestasis). Provided below is an algorithm for initial evaluation of neonatal cholestasis.

#### **Pediatric Liver Transplantation**

Infants with neonatal cholestasis should be promptly referred to a center with skill in pediatric hepatology. Furthermore, as biliary atresia is the most common indication for liver transplant, referral to a pediatric liver transplant center is also recommended. University of Virginia (UVA) Children's Hospital has been performing pediatric liver transplants since 1989. Starting in 2016, we have expanded our reach by partnering with Children's Hospital of Pittsburgh (CHP), which has performed over 1,200 pediatric liver transplants, more than any other center in the United States. The UVA/CHP Pediatric Liver Transplant collaboration is the first multi-center pediatric liver transplant program in the United States, working together to provide the highest chance of a successful transplant and increase access to care for transplant patients in the state of Virginia.

Under this program, CHP surgeons perform transplants at the UVA Medical Center and care is jointly managed by a CHP/UVA team. In addition to liver transplant, the program also excels in caring for children with chronic liver disease and those who require complex hepatobiliary surgical intervention.

Visit our website at https://childrens.uvahealth.com/services/pediatric-transplantservices/livertransplant.

For questions or referrals, email Michael Mendoza, MD, UVA Medical Director of the UVA/CHP Pediatric Liver Transplant program, directly at mvm4p@virginia.edu.

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## Medical Yoga at UVA

### Ina Stephens, MD

Associate Professor of Pediatrics University of Virginia

Mental health issues are epidemic among today's youth. Recent studies suggest that up to half of all teens have complaints related to stress, anxiety, and/or depression. In the United States, we have an unprecedented rise in the rates of child and teen suicide. The American Academy of Pediatrics is now recommending universal depression screening for all teens, a recommendation that promises to recognize patients at risk of severe mental health disorders, but also to increase the demand for mental health services among your patients and their families. In addition to patients presenting with primary mental health disorders, many patients with acute or chronic illness have difficulty adapting to their diagnoses or disabilities. Mental health services are needed to assure that such patients are able to achieve the best health possible. Medications are available to ameliorate mental health disorders, and many can be safely used in the primary care setting; individuals with more severe disorders may require referral to competent mental health professionals. However, many of these medications have unwanted side effects or are not familiar to the primary care physician, and mental health professionals are scarce in parts of Virginia. For these reasons and others, primary care physicians require additional approaches to respond to the challenges imposed by a growing number of patients requiring mental health support. Mindfulness practices have ancient origins in many cultures. Such practices share the essential effort of directing awareness to the present moment. Mindfulness practices, in a sense, allow one to witness, or observe, their thoughts and emotions, rather than immediately reacting or getting caught up in them. The practices help one understand that the individual is not simply his or her thoughts or emotions, thus empowering the patient to control negative ideation, or accepting such thoughts with grace and detachment. When undertaken regularly, mindfulness practices have been shown to confer an extraordinary number of health benefits. Mindfulness practitioners report reduced anxiety and depressive symptoms, improved cardiovascular health, better sleep, and better ability to adapt to social and personal challenges. An increasing number of studies have shown that yogic practices, such as mindfulness medita-

**Objective:** The reader will be able to incorporate yoga, meditation, and mindfulness as forms of medicine to prevent and treat symptoms. Review and discuss the relationship between stress to health and healing. Summarize the research behind medical yoga, mindfulness and meditation therapy. Discuss medical yoga therapy as complementary treatment for mental health and other chronic illness.

ACGME Competencies: Patient Care, Practice-based Learning and Improvement, Medical Knowledge, Interpersonal Communication Skills.

tion, can help ease stress, depression and anxiety, and in fact, may be just as effective in treating symptoms as antidepressants <sup>(1)</sup>. Western society has not traditionally embraced mindfulness practices, a fact which may contribute to the growing mental health epidemic. However, there is a growing movement to introduce simple methods of present moment awareness, techniques which can be incorporated into the daily life of even young patients. The most common practices include meditation and contemplation, mindful breathing, mindful walking (or eating, or in fact any action), deep breathing techniques and yoga asanas (postures and mindful movement). Meditation is difficult for most western pediatric patients, who are more used to an environment of nearconstant stimulation, but active mindfulness can be taught and embraced by nearly any child of school-age and beyond. It should be noted that Yoga is not a religion, but can deepen and benefit anyone in any religion. Yogic practices do not conflict with personal beliefs. Yoga is simply a tool that can transform oneself and promote conscious connection with oneself and the world.

Yoga is a particularly powerful mindfulness practice for promoting teen mental health (2). This ancient practice is markedly effective in improving health and well-being, provides stress relief and emotional regulation, and helps teens learn self-care. Self-care and learning to self-regulate are vital tools against mental illness and substance abuse, promoting a healthy body and mind <sup>(3)</sup>. Recent research has shown that yogic and mindfulness-based practices can positively impact the body in many ways, including helping to regulate blood glucose levels and keeping the cardiovascular system healthy. They have also been shown to have important psychological benefits, as the practice of yoga can help to increase alertness and positive feelings, and decrease negative feelings of aggressiveness, depression and anxiety (4–9).

Physiologically, mindfulness practices like yoga and meditation work by modulating the body's stress response systems <sup>(10)</sup>. They can help to calm the nervous system by enhancing parasympathetic tone and bringing the au-

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tonomic nervous system into balance. These practices decrease physiological arousal by reducing heart rate, lowering blood pressure, easing respiration and increased heart rate variability. Yogic practices have been shown to increase the body's levels of natural "happy neurotransmitters" such as GABA, serotonin, melatonin and oxytocin <sup>(11)</sup>. The practices can calm the limbic system and enhance the work of the prefrontal cortex, helping to regulate impulse control including how one reacts to stress, regulates emotions, enhances executive function and decision making. Yoga decreases the size of the amygdala, which is the brain's "threat" center – responsible for fear, anxiety and stress <sup>(12-15)</sup>. The body goes through several physiological changes in response to stress in fact >1400 biochemical reactions occur in response to stress, which subsequently results in alteration of our autonomic nervous system. If continued, these responses can cause significant perturbations, including inflammation and chronic illness. Signs of stress include apathy, lack of energy, difficulty making decisions, difficulty "keeping track" of things, feeling on edge, change in eating habits, sleeping more than usual or difficulty getting to sleep, insomnia, being more emotional, and substance abuse. Of note, symptoms of stress include mental illness and many other chronic illnesses, including chronic back pain, tension headaches, migraine headaches, neck pain, gastrointestinal problems (pain, diarrhea, IBS), palpitations, depression, anxiety, cognitive inhibition, impaired memory and weight gain.

Of particular importance as well is the fact that many typical habits of today's teens include enormous tech consumption, screen time, social media and less time spent in nature and outdoors. This prevents them from "truly being with themselves" and can lead to a feeling of disconnection from themselves and others. Yogic practices are about learning to pay attention - to one's self, one's body and to others. This can lead to a deeper awareness of one's internal state, and can help heal this disconnect. In addition, yogic breathing can calm the nervous system very quickly, and studies have shown that teens can use them effectively to relax before exams, help them sleep, and calm them down when they



are angry. When done regularly, focused and controlled breathing can help to control one's changing emotional state and stress level, allowing the mind and body to relax and move towards healing, resilience, connectedness and wholeness.

Yoga practice improves physical fitness and strengthens the respiratory system, making one feel stronger and more in control of one's body. It is not surprising that yoga is rapidly growing across America. Yoga studios are now found in most towns and cities, and yoga teachers can be found in studios, on the internet and on television. In addition to active mindfulness, yoga can also serve as a safe and effective exercise for nearly anyone, and a way to manage the many disorders caused by tightness of joints and muscles. In fact, in February of 2017, the Annals of Internal Medicine revised its clinical guidelines for chronic lower back pain to include yoga, mindfulness-based stress reduction and other non-pharmacologic treatments as front-line therapy for chronic lower back pain <sup>(16)</sup>. The availability of yoga to Americans will lead to the long-term integration of this practice into the lives of many individuals, with lasting benefit.

Although yoga is available to nearly anyone, there are individuals for whom yoga offers both special opportunities and special challenges. Patients with physical, or even mental, disabilities, for example, may not be well-served in the average commercial yoga studio. Conventional yoga teacher training does not prepare the teacher to deal with special patients, nor to maximize the effects of yoga for medical diagnoses. Thus has been born the specialty of Yoga Medicine, which offers the safest and most effective way to serve the patient with physical or mental disabilities.

UVA is among the first institutions in the US to offer a formal Medical Yoga Clinic, and one of the very few to offer this specifically for pediatric patients. In the Medical Yoga Clinic, physicians with special yoga certification prescribe and lead practices that can improve a wide range of disorders, in ways that are safe and non-invasive. Once taught, patients can perform the practices on their own, with follow-up as required by the clinic. Among the more tractable disorders for the Medical Yoga Clinic include anxiety, mild depression, chronic pain, musculoskeletal complaints, asthma, ADHD and high-functioning autism. Medical Yoga intervention may be integrated with any current therapy or medical regimen. Yoga practices with particular focus on mindfulness offer a safe and effective intervention for a growing number of pediatric patients. For a thorough review of Medical Yoga Therapy, see the following article <sup>(17)</sup>.

Referrals to the Medical Yoga Clinic at UVA can be made by calling 434-924-5321.

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# VIRGINIA • PEDIATRICS Innovations in Pediatric Diabetes at UVA: The future of diabetes is here

## David R. Repaske, PhD, MD Division of Endocrinology and Diabetes Department of Pediatrics University of Virginia

We are entering a new era of innovations in diabetes management that is the result of both new technologies and new discoveries about the pathophysiology of diabetes. However, until these new developments make their way into clinical practice, it remains critical to provide state of the art care for pediatric patients with diabetes. There are short-term complications of diabetes, hypoglycemia and DKA, that most often result from not taking insulin carefully, a particular challenge for adolescents that sometimes have diabetes as a low-level priority in their lives. There are also long-term complications from chronic hyperglycemia including coronary artery disease, neuropathy, peripheral vascular disease, nephropathy, and retinopathy. Children with diabetes have their diabetes complication clock ticking from a younger age, making it all the more important to maintain euglycemia to avoid early development of these long-term complications.

At UVa we are investing in resources for state of the art care in our diabetes program and at the same time bringing new technologies to push the boundaries beyond state of the art. We are heavily involved in research that spans development of new technologies such as the "artificial pancreas", understanding of the genetic susceptibility to development of type 1 diabetes, modification of the immune system to stop autoimmune attack before type 1 diabetes can develop, and understanding and predicting the risk for development of metabolic syndrome and type 2 diabetes.

We are proud of our clinical approach to diabetes and we were recognized this year by our ranking in the US News and World Report Best Children's Hospitals Endocrinology and Diabetes programs. We have a team approach to diabetes with physicians, nurse practitioners, diabetes nurse educators, dietitian nutritionists, social workers and psychologists. With a new diagnosis, we typically admit the patient for 18 to 24 hours (after resolution of DKA, if present) for teaching. They are seen by the attending and fellow, the diabetes educator, the dietitian, and the Objective: The reader will be able to discuss UVA's innovations in Pediatric diabetes clinical care and in diabetes research. ACGME Competencies: Patient Care, Practice-based Learning and Improvement, Medical Knowledge.

social worker. The educator provides backaround information on diabetes and how it is managed while the floor nurse guides the family through the practical aspects of counting carbs, checking blood glucose, and calculating and administering the insulin doses. The families follow up in 1-2 weeks as an outpatient and see the same team members that they saw in the hospital. This ensures continuity both for the family and for our team members and we can continue the initial education seamlessly in the outpatient setting. In addition, families have daily phone conversations with our diabetes nurse educators about blood glucose values and any necessary fine-tuning of insulin doses until that first visit, and then ongoing opportunity for phone support, as needed.

Diabetes clinic is held in Charlottesville and in Winchester to minimize the burden of taking time off of school and work for those who live in Northern Virginia. In order to provide full serve in both locations, physicians and a nurse practitioner travel to Winchester periodically and the diabetes educator, social worker and dietitian will see the patients at that location by telemedicine over an extremely high quality secure video link. We have a monthly diabetes support group for our patients and simultaneously hold a parent support group, or a parent advisory group meeting to facilitate feedback and improvement for our program. And the ultimate diabetes social experience, summer diabetes camp, is led by Dr. Melissa Schoelwer.

We have developed several diabetes clinics for special types of diabetes patients. For type 2 diabetes patients, pre-diabetes patients, and obese patients at risk for progressing to type 2 diabetes, we have our Fitness Clinic that is for children and adolescents with BMI at or above 85% ile. The core program is a 6 month lifestyle intervention program coupled with screening (and appropriate referrals) for co-morbidities that are often associated with obesity. Fitness Clinic is held in Charlottesville, Orange, Culpeper, Fishersville, Harrisonburg, and Winchester. GoGirls is a Zumba exercise group and life skills program that supports the Fitness Clinic and is led by Dr. Christine Burt Solorzano. And Dr. Kelly Mason has established a multidisciplinary clinic with Pediatric Pulmonology to evaluate and treat diabetes in patients with cystic fibrosis.

We have integrated technology into our diabetes clinic in that we upload insulin pumps, continuous glucose monitors (CGM), and blood glucose meters at every clinic visit in order to do an efficient and thorough analysis of home blood glucose control. Approximately 33% of our patients are using insulin pumps and almost 50% are using CGM regularly. Insulin pumps work very well for babies and toddlers as they can deliver much more accurate small doses, in increments of 0.025 units, than possible with syringes or insulin pens, resulting in much improved glucose control. CGM monitors have a tiny sensor under the skin and are worn for 7-10 days. They report blood glucose readings every 5 min and thus the patient goes from, say, 4 to 6 blood glucose checks per day to 360 blood glucose readings per day. Smartphone apps can receive and analyze the CGM data to sound an alarm for impending high or low blood glucose, and can send a mirror image of the data to a parent, teacher, nurse, or friend so that others can help support good diabetes management. The CGM also add a dynamic aspect to blood glucose assessment for insulin dosing decisions: If the blood glucose is elevated but falling less insulin is needed than if the blood glucose is equally elevated but rising.

We are introducing a paradigm shift in outpatient diabetes management by remotely monitoring our patient's CGM data from home and school. From the CGM data, we can accurately predict the hemoglobin A1c and estimate the risk for hyperglycemia and/ or hypoglycemia remotely from the patient's home between visits. If a patient has excellent control of blood glucose and a predicted A1c at goal with a low risk of hyperglycemia or hypoglycemia, we can safely allow them to skip a diabetes clinic visit. On the flip side, if diabetes management suddenly becomes

less controlled, we don't have to wait for the next three-monthly appointment, but rather can call, have a telemedicine visit, or a clinic visit to troubleshoot within days. This customized diabetes visit frequency is a new form of personalized medicine. And it provides a new incentive for good diabetes management: the ability to skip a clinic visit!

Another example of innovative use of technology that we are developing is an inpatient insulin bolus dose calculator in our Epic EMR to ensure accurate insulin dosing, especially in areas of the hospital less familiar with insulin therapy. The nurse simply inputs the current blood glucose value and the grams of carb to be eaten and the calculator considers the time of day and previous insulin dosing to determine the appropriate bolus insulin dose.

And, we are very active in research working toward better therapies and a cure. Dr. Mark DeBoer and Dr. Melissa Schoelwer are collaborating with the UVA Center for Diabetes Technology in developing and testing the technology for bringing the artificial pancreas to children. The artificial pancreas uses a CGM sensor to monitor blood glucose and a computer algorithm (initially in a free-standing computer, then in a cell phone, and now built into an insulin pump) to regulate the amount of insulin delivered by a pump based on the moment to moment need for insulin, just as the normal pancreas does. The latest algorithm was tested in January by Drs. DeBoer and Schoelwer at a 48 hour ski camp for 13 to 18 year old patients to try to stress the system under conditions of cold, altitude and vigorous physical activity. Data is still being analyzed, but it appeared to have performed wonderfully. A previous study by Dr. DeBoer of the artificial pancreas vs. conventional pump therapy in younger children 5 to 8 years old showed excellent promise and safety with increased time in target blood glucose range with lower mean blood glucose and no increase in hypoglycemia.

Dr. Steve Rich, Director of Public Health Sciences at UVA, has identified 40 genetic loci that predict 90% of the genetic risk for development of type 1 diabetes. Dr. David Repaske is collaborating with Dr. Rich in a study to identify children and adolescents at high genetic risk for development of type 1 diabetes with several goals in mind: to provide anticipatory guidance to high risk families to prevent potentially life threatening development of DKA, and to identify a cohort of potential subjects for clinical trials of strategies to prevent or delay development of diabetes. This study is being piloted at the UVA primary care pediatric clinics with plans to expand to other sites across the Commonwealth. Dr. Repaske is working with Dr. Larry Lum and Dr. Dan Fowler in Immunology at UVA on a strategy to interrupt development of diabetes. Lymphocytes from a person who is in the early antibody positive (but not yet hyperglycemic) stage of diabetes will be isolated and lymphocytes that can dampen autoimmunity will be isolated, amplified and returned to the patient with the goal of suppressing or stopping the autoimmune attack on the islet cells in the pancreas. If successful, this could be the cure that everyone is looking for.

The approach of our pediatric diabetes service is innovation: Innovation in current clinical care for patients with diabetes to support them and their families in good diabetes management, accompanied by innovation in research that will bring us closer to a cure.



## VIRGINIA • PEDIATRICS Chronic Lung Disease Associated Pulmonary Hypertension- The Next Epidemic?

Michael A. McCulloch, MD

Associate Professor University of Virginia Children's Hospital Department of Pediatrics, Division of Cardiology Medical Director, Pulmonary Hypertension Program **Objective:** The reader will be able to discuss the incidence/prevalence of bronchopulmonary dysplasia and pulmonary hypertension, and the factors that worsen and improve long-term outcomes in these fragile patients following discharge from the neonatal intensive care unit. **ACGME Competencies:** Patient Care, Medical Knowledge.

According to the Virginia Department of Health, approximately 100,000 deliveries occur in Virginia annually, of which nearly 8% are complicated by low birth weight (less than 2500 g) and 1.5% by very low birth weight (less than 1500 g). Due to marked advancements in neonatal care over the last several decades, average discharge survival rates have improved to 55% for 24 week gestation neonates and 92% for 28 week gestation.1 However, as many as 68% of neonates born at less than 29 weeks aestation are diagnosed with bronchopulmonary dysplasia (BPD)<sup>1</sup> and between 18 to 43% of those neonates develop secondary pulmonary hypertension.<sup>2-4</sup> The significance of this patient population's vulnerability becomes abundantly clear in mid-term follow up papers demonstrating 2-year mortality rates up to 40%.5,6

A myriad of reasons exists for these sobering data. Echocardiographic assessments of right ventricular function and pressures are commonly inaccurate<sup>7</sup>, complicating the diagnosis of right ventricular dysfunction and pulmonary hypertension. Aspiration of oral or gastric contents are a frequent source of recurrent lung injury and oftentimes clinically silent.<sup>8</sup> Left ventricular diastolic dysfunction9 and pulmonary vein stenosis<sup>10</sup> can significantly complicate the care of BPD patients but are less common and often go unrecognized. Most importantly, however, is the incomplete understanding of BPD pathophysiology<sup>11,12</sup> and a lack of data-driven guidelines on how to care for these patients once they are discharged from the hospital.<sup>13-16</sup>

The World Symposium of Pulmonary Hypertension classification system clusters different types of pulmonary hypertension with similar pathophysiology expected to have similar clinical response to therapies. Chronic lung disease/ BPD was recently added within the 'Developmental Lung Disease' subgrouping of group 3 pulmonary hypertension which also includes its closest adult correlates of chronic obstructive pulmonary disease and emphysema.<sup>17,18</sup> As group 3 pulmonary hypertension is a 'capillary' level disease process with associated regions of incomplete gas exchange, the most recent guidelines clearly state "there is no specific therapy for pulmonary hypertension associated with lung diseases"18 because systemically administered pulmonary vasodilators (i.e. sildenafil and bosentan) have proven to worsen gas exchange in several adult studies.<sup>19-21</sup> While all clinicians recognize babies are not small adults, it would be foolish to extrapolate adult criteria and treatment regimen for all

other types of pulmonary hypertension but not consider them for this group. Accordingly, our pulmonary hypertension team thoroughly evaluates each initial inpatient diagnosis of BPD and pulmonary hypertension for the above sources of lung injury and goes to great lengths to rule out or treat these problems. Any evidence of interstitial lung water prompts initiation of diuretics and or concentrated formula and nasal cannula oxygen is prescribed for saturations less than 92% due to the BPD patient's profound pulmonary vasoconstrictive response to hypoxia.<sup>22</sup> Pulmonary vasodilators are initiated only if right ventricular failure persists despite addressing all other issues.

Guidelines for treating outpatients with BPD are limited to those requiring invasive ventilation but are uniformly based on expert opinion without significant supporting data.<sup>23</sup> In general; however, a statement from the American Thoracic Society supports the concept of a 'medical home' in addition to the use of standardized discharge criteria, training of at least two family members in mechanical ventilator care, an awake and trained caregiver 24 hours a day, recurrent ongoing training of caregivers, regular manufacturer outlined ventilator maintenance, continuous pulse oximeter monitoring and du-



plication of all ventilator equipment, including the ventilator. While following these recommendations would be ideal, they are not uniformly covered by insurance, are plagued by home mortality rates of approximately 20%,<sup>24</sup> and do not address those patients not receiving mechanical ventilation.

Further complicating the care of this patient population is a nearly 40% incidence of acute kidney injury in very low birth weight infants,<sup>25</sup> which is associated with systemic hypertension and chronic kidney disease.<sup>26</sup> The only nephrology guidelines for premature infants call for earlier monitoring for systemic hypertension and "follow up" in any patient who developed AKI.

In response to these problems, the University of Virginia's Pediatrics Department has developed a multi-disciplinary clinic to care for former premature infants with chronic lung disease and pulmonary hypertension. By including members from our cardiology, pulmonology, complex care, nephrology, nutrition, and rehabilitative care divisions, our clinic will provide a 'medical home' focused on providing care for the patient as a whole. Though not a new concept, the medical home has received a growing level of attention as the average pediatric patient is becoming increasingly complex. Goals of improving outcomes, decreasing emergency room visits and 50% hospital readmission rates common in the first year of life,<sup>27</sup> decreasing parental loss of work, increasing family satisfaction and decreasing family stress are as true now as they were when such multi-disciplinary pediatric clinics were initially conceptualized nearly 25 years ago.<sup>28</sup> However, in the current era, this degree of care is exceedingly difficult to provide in a busy pediatrician's office and is only likely to succeed within a large hospital setting such as the University of Virginia, where the institution is able to utilize the same level of resources in outpatient management as were required during their initial hospitalization. In the 21st century, it is simply not acceptable to pour untold resources into a newborn during their NICU course and then simply be satisfied that a child 'survived' the admission. The same level of care must be provided after discharge from the NICU to ensure a child is able to live up to their full potential.

A major challenge this arrangement poses is the potential for marginalization of the primary care clinician.<sup>29</sup> On the contrary, our intent is to have the frontline community providers view this clinic as an adjunct to their own clinics, helping absorb the initial time, acuity and resource intense period following NICU discharge. Most patients are expected to progressively transition out of this clinic by their 2nd birthday with guidelines to maintain a trajectory of healthy growth and development. Referring providers can call the University of Virginia Division of Pediatric Cardiology office to schedule an appointment with our pulmonary hypertension team and start the process.

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# The Annual Leadership Forum Top 10 Resolutions

Following are the top 10 resolutions, which can be viewed in more detail at http://bit.ly/2GNfYIV:

- 1. Schools as Gun-Free Zones Arming Teachers is not the Answer!
- 2. Creation of a Suicide Prevention Task Force and Resources for Pediatricians, Healthcare Organizations, Schools, and Community Organizations Who Serve Children and Adolescents
- 3. Gun Restraining Order
- 4. The AAP Setting the Standards for Marijuana Regulations
- 5. Funding and Support for Autism Therapy
- 6. Granting Candidate Fellows the Right to Vote in AAP Elections
- 7. Increasing Immunization Rates by Universal Access to Immunizations
- 8. Promotion of Safe Gun Storage
- 9. Advocating for Universal and Affordable Contraception
- 10. Opioid Prescription Policy Statement

The top 10 resolutions will be referred to areas of the Academy with related expertise for a review of potential action.

To learn about the Academy's efforts to address the 2017 resolutions, visit http://bit.ly/2HOxPyr.

Look to the May issue of AAP News for additional coverage of the 2018 ALF.

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