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Jeffrey Bienstock, MD, FAAP
President, NJAAP

Growth, Learning & Sharing

Dear Member,

As the NJAAP Chapter enters the Fall of 2017, I want each of you to remember that while other associations may be shrinking, our Chapter continues to grow. As of September, we number over 1,700 pediatricians and other pediatric healthcare professionals, located throughout every county in New Jersey. Now more than ever, we need to Get Involved, and Stay Involved. As a chapter, we continue providing a strong voice on behalf of children, the adults in their lives and the pediatricians who care for them.

The Chapter assists us in accessing the most current information and tools that help improve the health outcomes of the patients for whom we care, support parents and caregivers, and provide ample opportunity to participate in myriad programs including:

- Bright Futures
- Child Abuse & Neglect Prevention
- CCHD Screening
- Zika
- Identification of Human Trafficking victims
- Immunization
- Lead Poisoning Prevention
- Lupus
- Medical Home
- Mental Health
- Obesity
- Oral Health and Zika

NJAAP offers members a wide array of continuing education and event opportunities (CME & MOC), both online and in conference. Our next major conference, the 26th Annual School Health Conference, will take place on Wednesday, October 18, 2017 at The Palace at Somerset Park, Somerset, NJ. The conference will consist of plenary and workshop offerings designed to aid pediatricians, their practice teams and other allied health care professionals. MARK THE DATE! http://njaap.org/events/school-health/

As each of us progresses through our careers, we need to look toward supporting the professional growth of the next generation of pediatric leaders. Our Chapter is always in need of MD champions to support our peer-to-peer model. For this, we look to the “experienced” docs to actively encourage the next generation of MD Champions to get involved and stay involved. Please join me in an effort to share all that we have learned with these younger physicians so that they too can further establish a firm foundation of knowledge on a wide range of topics from caring for sick children to acquiring the practice management skills necessary to run and grow a successful practice.

Continuing the “sharing” conversation, I encourage each of you who have not done so to download the New Jersey Pediatrics app. This app is free from any app store. It offers a seamless way to access and share articles and news from around New Jersey. To download, simply enter “New Jersey Pediatrics” into the search box. Simple and easy, no hassles.

And speaking of hassles, NJAAP members are encouraged to fill out Hassle Factor Forms to report any coverage, administrative and claims processing problems. And now, there is even a new Hassle Factor Form available for just retail base clinics. Both forms can be found in the Members Only area at www.njaap.org.

Thanks for playing an important role in NJAAP.
Involvement—The Domino Effect—Medicaid & Making a Difference

Achieving the NJAAP mission for optimal health for all children relies directly on access to quality pediatric health care—particularly for the most vulnerable children—and unwavering support for the pediatricians caring for them. NJAAP offers a dynamic and respected voice in advocacy efforts and routinely interacts with legislators on pediatric health care issues. In partnership with many public and private partners, NJAAP provides members with multiple resources: MOC and CME education, technical assistance, and time-appropriate access to mental health hubs for pediatric mental, emotional and behavioral health services for all children. These hubs, located in every county in NJ, are funded by the New Jersey Department of Children and Families and offered at no cost to pediatric practices. See the back cover to learn how to register with one of these hospital-based mental health hubs in your area.

The Domino Effect

Our state’s most vulnerable populations rely on Medicaid for health care coverage. Last year’s NJ Medicaid expansion enrolled an additional half million individuals. Exactly how many of these individuals are children is not yet quite clear. An insurance card alone does not guarantee access and it’s access to mental health hubs for pediatric mental, emotional and behavioral health services for all children. These hubs, located in every county in NJ, are funded by the New Jersey Department of Children and Families and offered at no cost to pediatric practices. See the back cover to learn how to register with one of these hospital-based mental health hubs in your area.

NJ AAP is working with our advocates, several legislators, and a host of partners, who have created a document entitled Medicaid 2.0—Blueprint for the Future. We are preparing to reach out to the new administration to ensure pediatric issues move to the forefront of New Jersey’s legislative agenda. How can you become engaged?

- Contact NJ Medicaid Provider Services to arrange to have a training specialist come to your office to address your claim challenges. 800-776-6334
- Tell us your experiences or barriers to providing care for patients working with Medicaid and VFC
- Visit your legislator. Offer to be a resource on pediatric health issues, and let them know of barriers to access and quality care. An NJAAP staff member can coordinate the meeting and join you. Don’t have time for a visit? Call your legislator and speak to them or one of their staff, or write them
- Write a letter to the editor of your local paper highlighting pediatric health access issues

We continue meetings with key stakeholders to influence improving pediatric Medicaid support on behalf of NJ’s children and our members. We have new opportunities to address the challenges, join us in these efforts. And speaking of joining together, along with NJAAP leadership, we hope to see you our October 18th Conference addressing the needs of pediatricians and school nurses. Bring a colleague. Find registration details at www.NJAAP.org.

Thank you for all you do.

Warm Regards,

Srividya Naganathan, MD
Christine Seminara, MD
Puthenmadam Radhakrishnan, MD, MPH, FAAP
Indira Amato, MD
Jeanne Craft, MD
Ernie Leva, MD
Christine Seminara, MD
Sonia Varma, MD

Fran Gallagher, MEd
With summer over and school restarting, now is a good time to again discuss the changing world of Pediatrics and the importance of understanding the trends and keeping ahead of the changes.

I.T. dominates the current era of changes; the days of the paper chart are rapidly diminishing. Many pediatricians have transferred over to electronic records as an aid to billing and documentation; fewer have transferred over to aid patient care and better manage their population of children.

Not yet required by Medicaid, but very soon becoming part of Medicare, is payment based on population health data.

Despite what happens with ‘health care reform’ there will be continued movement to pay for care management, reduced hospital and ED care and for evidence of optimizing health status. Electronic records provide the infrastructure necessary for such payment schemes and care delivery. Using Electronic records, a provider can quickly determine how many asthmatics are in the practice, how many children have developmental delays and identify which children are overdue for immunizations. The Electronic record can detail children with asthma who have not had a visit in three or six months, and how many children with ADHD are maintaining regular visits for follow-up.

Electronic records are also key in becoming a certified National Committee of Quality Assurance (NCQA) patient-centered medical home. Medicaid and commercial insurance will be paying bonuses or increased fee for service for practices that demonstrate competence in providing care coordination to children with chronic diseases and other issues including obesity and mental health problems, which are now categorized as chronic conditions.

NJAAP will be working with New Jersey Institute of Technology (NJIT) on supporting pediatricians interested in moving into the electronic record era.

The most recent New Jersey Medicaid waiver was granted initial approval by CMS. It includes provisions for telemedicine, especially for mental health, and for integrating mental health and physical health in terms of coding and reimbursement. We will know more about this in the coming months. There may also be an opportunity to work with Medicaid to bring back the enhanced payment structure (parity payment) that existed a few years ago as part of the two year trial by the federal government.

NJAAP has a number of new grants aimed at improving quality of care. A recent grant looks at Lupus as a model for chronic disease care and will be enrolling practices shortly. We are part of a national collaborative to improve adolescent preventive health services. We continue to support the mental health /pediatric psychiatry collaborative that will be expanding to every county in NJ over the next few months. We have grants submitted for human trafficking and medical home. We continue to expand the oral health initiative as well as our work in violence prevention, food insecurity and social determinants of health.

Please visit www.njaap.org or contact us to learn how to become involved.

Sincerely,

[Signature]
Recognizing Child Victims of Sex and Labor Trafficking

Jordan Greenbaum, MD
Stephanie Blank Center for Safe and Healthy Children
Children’s Healthcare of Atlanta

Introduction:

Trafficking of children for the purpose of labor or sexual exploitation is a global public health issue, with adverse consequences that impact victims*, families and communities, as well as whole societies. Trafficked children are at risk for a variety of physical and mental health problems ranging from sexually and non-sexually transmitted infections, to HIV/AIDS, unwanted pregnancy, complications of abortion, and substance misuse. They may experience serious physical injury from assault or work-related accidents, post-traumatic stress disorder, or anxiety and depression with suicidality. Malnutrition may be seen, as may exacerbations of untreated chronic diseases. Any of these problems may bring a child to the attention of healthcare professionals (HCPs).

According to U.S. federal law, child trafficking involves: “The recruitment, harboring, transportation, provision, obtaining, soliciting or patronizing of a person for the purpose of a commercial sex act (any sex act on account of which anything of value is given to or received by any person) using force, fraud, or coercion, OR involving a child less than 18 years of age.”

The commercial sexual exploitation of children (CSEC) is very similar to sex trafficking as it involves sexual crimes against minors committed for economic reasons. CSEC may take many forms, including prostitution controlled by a 3rd party (e.g. a ‘pimp’), prostitution without 3rd party involvement (sometimes called ‘survival sex’ when described in the homeless/runaway population), production of child sexual abuse materials (formerly called, ‘child pornography’); engaging a child in a sexually-oriented business, exploiting a child in the context of travel/tourism (“sex tourism”) and forced marriage.

Labor trafficking may involve a variety of work settings including domestic services, work in agriculture, manufacturing, or the food and hospitality industry, or begging and peddling (e.g. magazine sales). Children may be exploited in the construction business, health and beauty industry or in textile production. Examples of sex and labor trafficking are shown in Table 1 below.

Victims may live in the country in which they are trafficked (domestic trafficking), or be brought to the US from other nations (transnational/international trafficking). They may be female, male or transgender, of any socioeconomic status, race or religion. Victims originate from all areas of the world, although the main ‘source countries’ for the U.S. are the U.S., Mexico and the Philippines. While trafficked children may be of any age, the most common age group of those identified is early to middle adolescence. Many have one or more vulnerability factors at the individual, family, community or societal levels. Homelessness, runaway status, substance misuse, a history of sexual or physical abuse, lesbian/gay/bisexual/transgender status (LGBT), family violence and dysfunction, poverty, limited education, limited community resources, migration and unaccompanied status, and gender bias/discrimination all increase the risk of trafficking and exploitation.

The prevalence of human trafficking in the U.S. and the rest of the world is unknown as reliable estimates are lacking. The International Labour Organization (ILO) has estimated that 5.5 million children are involved in forced labor, which includes child trafficking. In addition, studies on survival sex among the large population of runaway homeless youth suggest rates of 9-28%. While a great deal of public attention is paid to American adolescent female victims of sex trafficking, it is important to appreciate that other groups are also vulnerable to sex and labor trafficking, including boys, lesbian/gay/bisexual/trangender (LGBT) youth and foreign-born children. The true numbers of victims in these groups is unknown but their numbers are

Table 1: Examples of child trafficking

<table>
<thead>
<tr>
<th>Example</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>14-year-old Guatemalan male working 16 hour days on chicken farm; identification documents held by farm owner, all ‘wages’ kept by owner; threatened with deportation if tries to escape</td>
<td>16-year-old female brought to US by ‘boyfriend’ and forced to work in cantina having sex with customers, forced to drink alcohol, use drugs to encourage customers to spend money</td>
</tr>
<tr>
<td>13-year-old female exchanges sex with boys in school to obtain money for jewelry, clothes</td>
<td>15-year-old homeless male exchanges sex with men/women customers on the street to obtain money for food, drinks, shelter</td>
</tr>
<tr>
<td>25-year-old male convinces 16-year-old female to dance at sex club</td>
<td>17-year-old Nigerian female accepts job in U.S. as ‘nanny’; forced to work 15-hour days cleaning and caring for children; not allowed to leave residence or contact family; not paid wages; sexually assaulted by male of home.</td>
</tr>
</tbody>
</table>

“In this article the word, ‘victim’ is used in the legal sense and refers to a person who has been harmed as a result of a crime or other event. It is not intended to imply any subjective interpretation of the person's feelings about their situation or imply any judgment about that person's resilience.”

continued on next page
likely underestimated due to priorities in investigation, skill in investigation and cultural beliefs.\textsuperscript{33}

Children and youth may be recruited into labor or sex trafficking situations through a variety of means, including false romance, false promises of work or a ‘better life’, offers to assist a child with a subsequent demand for ‘repayment’, debt bondage (occurs when victim accepts offer of loan) and because of high interest rates, low pay, and employer manipulation is unable to pay off the loan,\textsuperscript{34} offers to provide for survival needs or luxury items, gang involvement, abduction and violence.\textsuperscript{35, 36} Similarly, conditions children provide for survival needs or luxury items, gang involvement, abduction and violence.\textsuperscript{35, 36} Similarly, conditions children experience during their period of exploitation vary in terms of level of violence, degree and type of psychological manipulation, presence of threats, experiences of deprivation and isolation, and access to medical care.\textsuperscript{7, 28, 35, 37, 38} Many children are not associated with a ‘pimp’ or other controlling figures.\textsuperscript{28-30, 32} This is especially true among children involved in survival sex. Others may be under the control of a trafficker at some points, and not at others.\textsuperscript{29} Regardless, adversity, stress and uncertainty are ubiquitous among trafficking victims.

**Clinical Presentation**

While the ability to access medical care among labor-trafficked youth remains largely unknown, current research suggests a relative ease of access among sex trafficked youth in the U.S.\textsuperscript{5}. In one study of adolescent and adult female sex trafficking survivors, nearly 88% reported having had contact with HCPs during their period of exploitation.\textsuperscript{6} Thus, HCPs may serve as liaisons for victims to access services.

It is important for providers to be able to recognize high-risk children. Unfortunately, this is not always easily accomplished as victims typically do not self-identify.\textsuperscript{2} Shame, humiliation, distrust, fear, concern about child protective or law enforcement involvement, worries of deportation, and lack of recognition of their exploited status may prevent disclosure.\textsuperscript{2} Contributing to the difficulty in victim recognition is the lack of a ‘typical’ clinical presentation.

A child victim may present for medical care alone, with their trafficker, with one or more other victims (who may have been sent by the trafficker to monitor the patient and ensure he/she does not disclose their status), or with parents or relatives (who may or may not be aware or involved in the trafficking).\textsuperscript{17} They may seek medical care for their own children, as in the case of teen mothers who are being exploited or parents who are labor trafficking victims. They may seek attention at emergency departments, urgent care clinics, other ambulatory clinics, Planned Parenthood or a primary care clinician.\textsuperscript{8} And victims may present with any of a variety of physical or behavioral health complaints. These complaints may be related to adversity experienced as a consequence of their exploitation, or may be related to untreated chronic medical conditions. Thus a 14-year old sex trafficked male may seek care for symptoms of an STI, or a 13-year-old female sex trafficking victim may seek care for acute diabetic ketoacidosis when she has run out of her medication.

Since the manner and site of presentation may vary so tremendously, it is helpful for HCPs to be aware of possible indicators of child trafficking. Importantly, these factors may or may not be present and may or may not reflect a trafficking situation when seen. A child’s submissiveness in the face of an accompanying adult’s verbal dominance and irritability may indicate any of a variety of abnormal relationships, not necessarily one involving a trafficker and victim. However, when one or more indicators are seen, it is helpful for the HCP to consider the possibility of trafficking and to ask further questions. Some of these indicators are listed in Table 2 below and involve the behavior of the child and/or person accompanying the child, or involve factors identified in the child’s social history. Other potential indicators of trafficking include the child presenting with a chief complaint involving one or more common adverse effects of trafficking such as signs/symptoms of STIs, inflicted injury, dental complaints, work-related preventable injury, suicide attempt, malnutrition, exhaustion, symptoms of PTSD or other behavioral problems.

<table>
<thead>
<tr>
<th>Table 2: Potential Indicators of Child Trafficking\textsuperscript{1, 5, 10, 25, 39} (also see text)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child accompanied by unrelated adult or juvenile</td>
</tr>
<tr>
<td>Child or parent accompanied by domineering person who appears in hurry to leave; child/parent appear intimidated, fearful</td>
</tr>
<tr>
<td>Child or accompanying person provide inconsistent or unlikely history of events</td>
</tr>
<tr>
<td>Child does not know city they are in, or address where staying</td>
</tr>
<tr>
<td>Child with hotel keys, multiple mobile phones, large amount of cash</td>
</tr>
<tr>
<td>Child withdrawn and with flat affect; fearful; very anxious; intoxicated; or with inappropriate affect</td>
</tr>
<tr>
<td>Child with sexually explicit tattoos or tattoos with gang logo or man’s name</td>
</tr>
<tr>
<td>Child or family new to country, unfamiliar with language</td>
</tr>
<tr>
<td>Child or parent without access to identification documents, money</td>
</tr>
<tr>
<td>Child with one or more vulnerability factors for human trafficking (see text)</td>
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continued on page 8
To maximize the likelihood of obtaining accurate information and providing optimal care and resources, it is critical for the HCP to adopt a trauma-informed, rights-based, culturally sensitive approach to the potential victim of trafficking. This means making the best interest of the child the top priority during all interactions and when formulating plans. Many trafficked children/youth have experienced considerable trauma prior to, and during, their period of exploitation. A ‘trauma-informed approach’ involves considering the possible impact trauma may have had on the victim’s views of themselves and the world, on their thoughts, feelings and behaviors. Trauma may influence the way the child interprets the words and actions of the HCP, the way the child responds to others and the attitude they take toward receiving assistance. It is helpful for the HCP to keep in mind that all behaviors serve a function and the child’s withdrawn, depressed, inappropriately happy, cocky, belligerent or aggressive manner may represent a learned method of survival in a dangerous environment. With a trauma-informed approach, the HCP remains open, nonjudgmental, and empathic, builds rapport and patient trust, and empowers the child to participate in the medical evaluation process. Elements of a trauma-informed approach are described in Table 3.

Table 3: Components of a Trauma-Informed Approach to Medical Care

- Use strength-based approach that focuses on resilience and empowerment
- Speak with child alone, in a private, safe place
- Obtain informed consent after thorough explanation of processes (provide developmentally, culturally appropriate information in child’s native language)
- Explain limits of confidentiality/mandated reporting as relevant
- Encourage patient to express views, actively participate in process
- Minimize re-traumatization; ask only the questions needed to assess safety, health and well-being
- Allow patient option to choose gender of provider if feasible
- Have trained personnel present during exam to provide support
- Conduct safety assessment, create plan
- Make appropriate referrals, offer resources

Included in a trauma-informed approach is close attention to cultural beliefs and practices, with respect and humility guiding the actions of the HCP. No one can be an ‘expert’ on all cultures and subcultures, but awareness of the influence of culture on a child’s attitudes and actions and an open admission of a desire to respect a child’s culture may assist in determining optimal ways of communicating and help to build trust between HCP and patient. Finally, sensitivity to a child’s gender and sexual orientation will maximize the likelihood of the HCP being able to offer appropriate care and services.

Central to the idea of a trauma-informed approach is the awareness that questioning a traumatized person about their experiences may lead to anxiety and other symptoms of traumatic stress. Every effort needs to be made to minimize the re-traumatization of children during the medical visit. This can be facilitated by the HCP obtaining as much information as possible from sources other than the patient (law enforcement, parents, medical record). Thought should be given to the reasons behind each question the HCP asks the child, and the clinician should focus all questions on health, safety and other issues directly relevant to guiding the exam, patient counseling and referrals. While many states have mandatory reporting laws regarding suspected child sex trafficking, the goal of the HCP is not so much about obtaining a definitive disclosure of victimization as it is about identifying children at risk so that appropriate care and referrals may be made. Mandatory reporting laws do NOT require the HCP to be certain a child is a victim, only to have a reasonable suspicion of exploitation. Thus, if a child demonstrates several risk factors but does not actually disclose commercial exploitation, actions should still be taken to assist the child; this includes a report to authorities if the HCP has significant suspicion that trafficking has occurred.

Not all children with risk factors for human trafficking are being exploited. The HCP may need to ask additional questions to determine the level of risk for an individual patient. Such questions need to be asked in a sensitive manner, without bias, judgment or assumptions about answers. Examples of possible questions are listed in Tables 4 and 5 on the following page.

Exam and Diagnostic Testing

The physical exam and diagnostic testing need to follow the trauma-informed approach, with careful consideration given to explanations for each part of the process and informed consent for each step. Offering the child as many choices as possible helps to empower them to participate in the process, conveys respect and facilitates a sense of self-efficacy (“Would you like something to eat? Would you like a blanket? Do you want me to describe each step as I’m doing the genital exam or would you rather just play on the i-pad or watch TV?”). Frequent monitoring by the HCP or the chaperone for signs of patient distress will help minimize re-traumatization. This is especially important during the genital exam, collection of forensic evidence and when documenting injuries with photographs. If the suspected trafficker or someone working for the trafficker accompanies the child, they should be excluded from the exam. Components of the medical evaluation are listed in Table 6 on the following page. Details regarding the exam, sexual assault evidence kit, STI and other diagnostic testing, treatment and prophylaxis may

continued on next page
Reports and Referrals:

HCPs need to be aware of relevant laws and policies regarding mandatory reporting of suspected child trafficking, conducting exams without the consent of a guardian, etc., and resources are available. When making reports to authorities, it is important to emphasize that the child is a victim rather than an offender, as police and child protective service workers may or may not have received prior training on child trafficking. If the child is instead treated as a ‘child prostitute’ or ‘illegal immigrant’ they may not obtain access to critical victim services. In addition to making necessary reports, the HCP should consider appropriate victim service referrals, especially those related to health and safety. Decisions about referrals should be based on information gleaned from the history and exam, and on the needs/desires of the patient. If the HCP is not mandated to report to authorities, they may still make a report if the child consents.

Similarly, the HCP may contact the National Human Trafficking Resource Center (1-888-373-7888) to obtain answers to questions about trafficking, assistance for victims, and to make referrals for possible victim services.

Table 4: Questions for Possible Child Sex Trafficking

<table>
<thead>
<tr>
<th>Question</th>
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<tbody>
<tr>
<td></td>
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<tr>
<td>“I’ve talked to many kids who have runaway and are living on the streets. They have a very hard time getting the money to pay for things they need—food, clothes, a roof over their heads, maybe drugs….Some of these kids have told me they exchange sex for money or for something they need. Have you ever had to do that? (If yes, “Do you feel comfortable telling me about it?”)</td>
</tr>
<tr>
<td>“Have you ever exchanged sex for money to help someone else, say a boyfriend or a family member?” (If yes, “Do you feel comfortable telling me about it?”)</td>
</tr>
<tr>
<td>“Has anyone ever asked you to have sex with someone else?” (If yes, “Do you feel comfortable telling me about it?”)</td>
</tr>
<tr>
<td>“Have you or anyone else ever posted sexy photos/videos of you online for strangers to see?” (If yes, “Do you feel comfortable telling me about it?”)</td>
</tr>
</tbody>
</table>

Table 5: Questions for Possible Labor Trafficking (of child or parent)*

<table>
<thead>
<tr>
<th>Question</th>
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<tbody>
<tr>
<td></td>
</tr>
<tr>
<td>“If you feel comfortable, can you tell me a little about your work? What do you do? How long have you been working for this employer? Etc.</td>
</tr>
<tr>
<td>“Do you have control over your identity documents? Over your money?”</td>
</tr>
<tr>
<td>“Is the work you are doing what you expected to be doing when you were hired?”</td>
</tr>
<tr>
<td>“When you are not working, are you free to come and go as you please?”</td>
</tr>
<tr>
<td>“Where do you live? What is it like? Do you feel safe there?”</td>
</tr>
<tr>
<td>“Do you have any concerns about your work or living situation?” (e.g. long hours, no breaks, harsh conditions, no safety protection, dirty conditions, no water/electricity, etc)</td>
</tr>
<tr>
<td>“Do you owe anyone money, for example, your employer?”</td>
</tr>
</tbody>
</table>

* It is important to consider that many foreign national children and adults are very concerned about possible discrimination, arrest and/or deportation. So, it is very important to approach these questions sensitively. It may help to carefully explain that you are not working for the police, and you are not concerned with whether or not the child/adult has legitimate documents allowing them to be in the country. You are simply concerned that all of your patients and families know about their basic rights. Because many people coming into the country may be mistreated and taken advantage by others, you ask all your patients/parents about their living conditions to see if they need any help or resources. The HCP should be sure to emphasize that answering the questions is completely voluntary and whether or not they choose to answer questions, resources are available for them if they have concerns about their living and working conditions (be sure to have these resources available, be they hotline numbers, fact sheets about work rights and immigrant rights, or referrals to appropriate agencies/service organizations).

Table 6: Components of the Medical Evaluation for Possible Child Trafficking

<table>
<thead>
<tr>
<th>Component</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assess overall health, nutrition, appearance</td>
</tr>
<tr>
<td>Assess and treat acute/chronic conditions</td>
</tr>
<tr>
<td>Obtain sexual assault evidence kit as indicated</td>
</tr>
<tr>
<td>Document genital and extra-genital injuries</td>
</tr>
<tr>
<td>Offer STI, HIV, pregnancy testing; offer prophylaxis as indicated</td>
</tr>
<tr>
<td>Consider testing for endemic diseases of home country; consider other tests for malnutrition, etc. as indicated</td>
</tr>
<tr>
<td>Offer drug testing as indicated</td>
</tr>
<tr>
<td>Explain results of exam, ask child if they have any questions/concerns</td>
</tr>
</tbody>
</table>

If the HCP feels uncomfortable with the evaluation process, it may be preferable to defer the exam to a provider with specific experience in sexual assault (sexual assault nurse examiner, or child abuse pediatrician, for example). Advice for evaluating vulnerable immigrant children is also available.

Resources for Possible Child Trafficking

- National Human Trafficking Resource Center (1-888-373-7888)
- American Academy of Pediatrics
- The Children’s Defense Fund
- Child Welfare League of America

* It is important to consider that many foreign national children and adults are very concerned about possible discrimination, arrest and/or deportation. So, it is very important to approach these questions sensitively. It may help to carefully explain that you are not working for the police, and you are not concerned with whether or not the child/adult has legitimate documents allowing them to be in the country. You are simply concerned that all of your patients and families know about their basic rights. Because many people coming into the country may be mistreated and taken advantage by others, you ask all your patients/parents about their living conditions to see if they need any help or resources. The HCP should be sure to emphasize that answering the questions is completely voluntary and whether or not they choose to answer questions, resources are available for them if they have concerns about their living and working conditions (be sure to have these resources available, be they hotline numbers, fact sheets about work rights and immigrant rights, or referrals to appropriate agencies/service organizations).
guidance on referrals and reporting procedures and other resources. This hotline is available 24/7 and has interpreters for over 100 languages. The HCP may call for advice, even if not disclosing any identifiable patient information. They may also provide the hotline number to the child or parent, if the patient/parent desires this contact and it can be done safely (without trafficker's knowledge, for example). Other health-related referrals to consider include an easily accessible medical home, obstetrician, drug rehabilitation, behavioral health services, and specialty medical care.

The discussion with the patient/parent about referrals may also include counseling on healthy behaviors, harm reduction and general safety. For a child who admits to only intermittent use of condoms, the HCP may discuss STIs, HIV and the multiple purposes of condom use. This may lead to a discussion of contraception and a referral to an easily accessible medical home (teen clinic, for example). A child reporting frequent use of drugs may need brief intervention and a referral for full evaluation and treatment.4 A discussion of ways to stay safe when living 'on the street' may be extremely useful, as may specific referrals to local shelters, food pantries and drop-in centers.

The needs of trafficked children extend well beyond physical and mental health domains, and beyond the capabilities of an HCP to accommodate. Thus, it is critical to adopt a multidisciplinary approach to patient care, with the HCP working closely with law enforcement, child protective services and victim service organizations. It is useful to have a clinic/office/hospital protocol in place to guide the HCP in making the correct referrals and contacts, with specific local and national resources listed. These may include resources for housing, job training, employment assistance, education, legal services, and immigration assistance. Working with the patient, the provider can create an appropriate service and safety plan, using external resources with the child's consent.

Despite the extensive work by HCPs and other professionals when a trafficked child is identified, many victims return to their situation of exploitation one or more times. The causes of re-trafficking are multiple and may change over time. Lack of victim acknowledgement of victimization, poverty, threats, trauma bonds, hopelessness, limited options and the need to avoid a very dysfunctional family may contribute to the recurrence of exploitation. The HCP must consider this possibility when providing health and safety counseling and offering resources. Even if the child returns to a life of exploitation after the medical visit, this does not mean the HCP’s efforts have been in vain. The child’s experience of having a caring adult listen nonjudgmentally, empower the child to make choices, convey respect and empathy may lead that child to trust a future health professional and eventually exit the exploitative situation.

Conclusions:

Child sex and labor trafficking have profound consequences for the health and well-being of victims, and a major impact on families and communities. Healthcare professionals have an important role to play in recognizing children at risk, conducting trauma-informed assessments, offering services and providing appropriate resources. While re-trafficking is a common reality, the counseling and resources offered by the HCP may prove life-changing to a very vulnerable child.

References

continued on next page
37. Reid JA. Entrapment and enmeshment schemes used by sex traffickers. Sexual Abuse: J Research and Treatment 2016;28:491-511.

“In this article the word, ‘victim’ is used in the legal sense and refers to a person who has been harmed as a result of a crime or other event. It is not intended to imply any subjective interpretation of the person's feelings about their situation or imply any judgment about that person's resilience.”

CME Quiz on page 12
1. Trafficked children are at risk for which of the physical and mental health problems?
   a. Unwanted pregnancy
   b. Substance Use
   c. Non-sexually transmitted infections
   d. PTSD
   e. All the above

2. The most common age group of those children identified as being trafficked is:
   a. 18–19 years
   b. 16–17 years
   c. 10–15 years
   d. None of the above

3. In a 2014 study of adolescent and adult female sex trafficking survivors, nearly 88% reported having had contact with a healthcare provider during their time of exploitation.
   a. True
   b. False

4. Which of the following is not a potential indicator of child trafficking?
   a. Child or parent without access to identification documents or money.
   b. Child accompanied by an unrelated adult or juvenile
   c. Child provides an address where they reside
   d. Child with multiple cell phones.

5. A trauma-informed approach involves consideration of the possible impact trauma may have on a victim's view of themselves, their thoughts, feelings and behaviors.
   a. True
   b. False

6. Central to the concept of a trauma-informed approach is the awareness that questioning a traumatized person about their experience may lead to anxiety and other symptoms of traumatic stress:
   a. True
   b. False

7. The medical evaluation for possible child trafficking should include:
   a. Assessing and treating acute/chronic pain
   b. Assessment of overall health, nutrition and appearance
   c. Offering an STI, HIV and pregnancy testing
   d. Explanation of exam results
   e. All the above

8. Which of the following is not a key contributor to re-trafficking?
   a. Trauma bonds
   b. Poverty
   c. Hopefulness
   d. Threats

9. Should a healthcare provider report concerns of exploitation if a child demonstrates several risk factors but does not actually disclose exploitation?
   a. Yes
   b. No

10. Both the physical exam and diagnostic testing need to follow a trauma-informed approach that offers a clear explanation for each part of the process and thereby allows for an informed consent from the patient:
   a. True
   b. False

CME Instructions
Read the CME-designated article and answer the Fall issue, quiz questions above. Print your name and phone number and mail or fax this form within six months from the date of issue to: NJAAP CME Quiz, 50 Millstone Road, Building 200, Suite 130, East Windsor, NJ 08520 Fax: 609.842.0015

NAME ______________________________ PHONE ______________________________

EMAIL ______________________________________

Submitter must answer 8 of the 10 questions correctly to qualify for CME credit

Accreditation Statement:
This activity has been planned and implemented in accordance with the accreditation requirements and policies of the Medical Society of New Jersey through the joint providership of Atlantic Health System and the American Academy of Pediatrics, New Jersey Chapter. Atlantic Health System designates this live activity for a maximum of 1.0 MA PRA Category 1 Credits™. Physicians should claim only the credit commensurate with the extent of their participation in the activity. Atlantic Health System is accredited by the Medical Society of New Jersey to provide continuing medical education for physicians.
CME Activity

Trauma-Informed Pediatric Care

Steven W. Kairys, MD, MPH, FAAP
Chair, Department of Pediatrics
Jersey Shore University Medical Center

Background

Trauma affects children from all social classes in the United States. Although there is no one universal definition of trauma, a common one from the Substance Abuse and Mental Health Services Administration (SAMHSA) is instructive. 

“Individual trauma results from an event, series of events, or set of circumstances that is experienced by an individual as physically or emotionally harmful or life threatening and that has lasting adverse effects on the individual's functioning and mental, physical, social, emotional, or spiritual well-being.”

Epidemiological studies demonstrate the large percentage of children impacted by trauma. Child maltreatment data show that up to 10% of children have experienced physical abuse and Child Protection Services receives over 3.5 million referrals a year. While these data show only public reporting data, more inclusive data are derived from the Adverse Childhood Experiences (ACE) studies that originated at Kaiser Permanente 20 years ago. ACEs include such experiences as abuse and neglect, but also experiencing household dysfunction from domestic violence, parental substance abuse, parental mental health issues, incarceration, and/or complicated divorce. The data show that two-thirds of children have experienced one or two such adverse experiences during their childhood and that one-quarter have suffered three or more independent ACEs. Even more concerning is the fact that these numbers are increasing, as the latest studies now include severe economic hardship and disasters in the ACEs definition. 

As the number of children impacted by trauma increases, so does the potential for triggering overwhelming harm among them. The impact is well documented. Much of this trauma is now identified as toxic stress, which implies that the stress on the child is so severe or long standing that it overwhelms an individual’s normal coping and defense capabilities and leads to long term neurobiological and psychologic effects including: stress hormone dysregulation, poor attachment and socialization, poor self-efficacy, emotional disorders, trauma induced learning disorders and ADHD. Toxic stress often prompts poor coping strategies such as smoking, substance abuse, and over eating. The long term consequences, as traumatized children become adults, include major depression and suicide, substance abuse, criminal behavior, but also heart disease, chronic lung disease and early death. In fact, in those with three or more ACEs, the chance of living beyond age 65 is only 10% when compared to individuals with one or no ACEs.

Pediatric practices across New Jersey provide care to children impacted by prolonged exposure to toxic stress from adverse childhood experiences. It is the major childhood antecedent for so much psychological and physical morbidity and mortality to these children and to the adults that they will become. There is much that pediatric practices can do to be more informed themselves and then to inform the families in their care. This paper will present some important steps that can be taken for prevention through anticipatory guidance, as well as for screening to identify and support children who are victims of such toxic stress and trauma.

First step: Awareness/Self & Staff Education

An essential first step is to realize that trauma impacts large numbers of children and families in the pediatric practice. This realization needs to be practice wide and not only understood by the providers. Awareness begins by having practice team members see the child and family’s issues and behaviors in the context of coping strategies developed to survive such adversity, whether the traumas were in the past or are current and active.

This realization will not only lead to a more proactive stance with patients, with regard to communicating primary prevention through anticipatory guidance; it will also allow a constructive response and support for families in an effort to avoid re-traumatization by the practice. Also important is the realization that being involved and engaged with families experiencing distress can negatively impact the staff and providers themselves. Looking into ways to help yourself and your staff to positively deal with this vicarious trauma is advised.

Practice leadership needs to embrace this step since any change to be sustained will need its active support and oversight. Much of trauma-informed practice demands that the child and family feel empowered; that there is choice and collaboration in the decisions made; that children and their families are informed and an active part of the plans and care management; and that the electronic or paper records document such engagement and shared decision making.

Step Two: Practice-based Organizational Changes

Creating a Safe Environment:

Victims of trauma do not feel safe. They are hypervigilant and scan every new environment for evidence of potential danger. They are anxious and untrusting. Therefore, creating an environment that helps children feel physically, socially and emotionally safe is fundamental to a trauma-informed practice.

A safe physical space is well lit and secure, noise levels are monitored, signage is welcoming and positive, and written and play materials are engaging, interactive and understandable.

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A safe emotional space has staff that engage and are welcoming, and who positively support the children and families and make them feel respected. In a safe emotional space, staff are able to stay professional and have healthy boundaries with the families; they have learned how to handle conflict or problems that can arise.

A safe emotional space also implies trying to keep to the scheduled times and to openly communicate if delays occur. Staff should be trained to understand cultural differences, especially with regard to how different cultural mores impact perceptions of trauma and safety and privacy.

I. Training Clinical and Non-Clinical Staff:

- Training is critical to providers and staff being able to work as a team in providing trauma informed care. Training is best done as a team as part of staff meetings. Training includes content and process components. The office team needs to understand the reasons for the transformation and the background information about the prevalence and impact of trauma to families. Staff should be given the time to discuss their reactions and their own emotional responses to the information.
- Process education is the learning of different approaches to initiating positive relationships and supporting families in their care, welcoming and listening, understanding early cues of stress or anxiety and defusing such issues early and effectively.
- The whole staff has to embrace the changes for the changes to be impactful. Having one or two providers or staff that continue with approaches that are not constructive and do not feel safe will dramatically lessen the services that are provided.

II. Preventing Traumatic Stress to the Staff:

- It is very common for providers and staff that regularly care for children and families who are deeply impacted by trauma and toxic stress to internalize that distress. This is often insidious and not readily transparent. Such internalization can lead to fatigue and sadness, poor concentration and effectiveness, illness and absenteeism, emotional detachment, poor social interactions, and physical symptoms and illness. Such burnout is a sad response to trying so hard to help others but it is preventable and can be detected early. For many staff, the impact is increased if that staff has had trauma in their own past, or is currently living through complicated social and personal difficulties.

Many organizations that deal with trauma work with their staff on prevention approaches such as mindfulness training, yoga, and promoting healthy lifestyles through personal exercise and healthy nutrition. Others promote supervision that is reflective and directly asks about the effects of such trauma. Prevention and early identification of this secondary traumatic stress can increase staff morale and improve office function.

Each practice needs to develop its own approach based on its particular culture and traditions. Whatever the approach, the recognition of staff burnout as being real and likely, is a key factor in the initiation of such efforts.

Step Three: Clinical Practices

Prevention:

- Including aspects of trauma prevention into the anticipatory guidance content for well infant and child visits helps to educate families about positive parenting practices, approaches that support attachment, bonding, and promote resilience and strengths.
- Practices often have posters and routines that promote such themes, pamphlets and brochures about healthy child development and child rearing, and staff that are aware of community resources and support services for families with high risk of stress and distress. The AAP has a series of brochures, Connected Kids, each providing guidance on addressing childhood experiences related to trauma and distress.
- Anticipatory guidance should provide an understanding of infant temperament and differences in development; promote the importance of parent engagement, of positively responding to the infant and child’s actions (serve and volley) and of reading and spending one-on-one time each day with the child. In many ways, such preventive approaches not only give structured and evidence-based guidance to parents but also serve as one way to pick up cues about potential dysfunction with the family.
- Practices need to learn about the abundance of quality community resources that are available to the family- from the NJ Department of Children and Families (DCF) Family Success Centers, to early childhood education and day care resources, to family support networks and organizations. In NJ, each county has a Central Intake office with social workers available by phone to talk with families in need of local resources and support.

continued on next page
Screening for Trauma:

- Although there are no primary care screening tools specific for trauma, there are evidence-based tools that can be very useful for picking up clues about antecedent trauma. For young children the SWYC (Survey of Wellbeing of Young Children) is an age specific evidence-based screen that provides information about development, social and emotional issues, and also the family context. It is available for children ages 2 months–66 months, and is much broader in its application than other tools such as Ages and Stages; it is free of charge and available on the internet in English, Spanish, and a few other languages. The SWYC can be found at: www.floatinghospital.org/The-Survey-of-Wellbeing-of-Young-Children/Overview.aspx

- A second such broad pre-school social screen is the Parent Screening Questionnaire (PSQ). This tool screens for maternal depression, domestic violence, harsh parenting, parental stress and food insecurity. It is completed at the 2 month, 9 month, 15 month and the 2, 3, 4, and 5 year old well child visits. The tool is also evidence-based and very effective in detecting trauma and family distress. The tool can be accessed here: www.nciom.org/wp-content/uploads/2014/07/36-8-b-SEEK-The-Parent-Screening-Questionnaire-black-whit.pdf

- For older children the general screen Pediatric Symptom Checklist (PSC) will elicit behavioral and emotional concerns that could have a trauma basis. The PSC is completed by parents of children ages 6–18. There is also a companion screening for adolescents ages 11–18, called the PSC-Youth. The provider would then have to ask general questions about recent stressors or significant changes in the home. For example, children living through a natural disaster may only slowly exhibit symptoms of depression or anxiety many months after the events.

- There are specific trauma screens but most are not pertinent to primary care unless the provider has a specific focus on trauma. One that is beginning to be used in primary care is the Adverse Childhood Experiences Screen that was originally designed as a research tool but is now being used in primary care. A recent study in a general family practice showed that use of the ACE questionnaire found concerns in 62% of families and 22% of families had three or more ACEs.5

Whatever approach is used, a practice that is trauma-informed will ask open or closed questions about behaviors or mental health concerns that arise during a visit, since so many of these symptoms can have their basis in a background of new or long-standing trauma and toxic stress.

After Trauma is Identified

For many children and families the identification of trauma can make them feel more vulnerable and less safe. Thus the provider and the office need to feel safe to the child and family. Body language and empathic responses give a message of caring and support. Providers can help by taking the time to better understand the family dynamics, their strengths and difficulties, and their social support network.

The trauma-informed practice can best manage these families by the psychologic first aid acts of listening and empathy. Then education about trauma and its impact on physical and emotional health are very important to help the child and family begin to understand the broad impact about what has occurred. Discuss the importance of maintaining routines and structure, consistent meal and sleep times. Discuss that many children also react physically with abdominal pains or headaches. Help the family recognize that children pick up many of their cues from the parents and the parents need to recognize the way they themselves are dealing with the trauma and stress.

In New Jersey there are a plethora of community and state resources to help children and families. The State now has the Pediatric Psychiatry Collaborative, county-based mental health hubs that will help providers through consultative services, and help families screened by primary care practices to access the resources they need for addressing mental/behavioral health issues. As mentioned previously, Central Intake is a county specific source of support for families needing help with food or housing or day care or other general issues. Child Protection and Permanency (CP&P) is not only important when there are concerns about possible abuse and neglect, but also for accessing myriad local supports and services. Family Success Centers are a unique community-based model supported by the Department of Children and Families that assists children and families in avoiding future crisis. Details and contact information about some of these resources is included at the end of this review.

Lastly, see the family again to monitor and assist. These issues are most often chronic and will need time and ongoing support. Families love their children, but often lack the expertise or social capacity to provide adequate care for them, especially when trauma is involved.

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Does Trauma-Informed Care Make a Difference?

A recent review of 12 primary care interventions to prevent or treat traumatic stress in children was very positive. Review authors reported that parents found the focus very useful. Uniformly, practices improved their recognition of trauma issues, especially: domestic violence, maternal depression, parental substance use, lack of social supports and food insecurity. The authors found that these interventions added only one to two minutes to the length of the well child visits.

Conclusions:

Trauma-informed care is an important response to the epidemic of trauma and toxic stress that exists in our society. Such care does not mean a complete restructuring of primary care, but it does demand that the practice make conscious and proactive decisions about how to prevent, screen and manage victims of trauma, and how best to support and educate such children and families. It is important to be mindful of issues of safety and privacy and sharing control with the child and family. Take time to explain before you do, being mindful of the emotions and responses that often are elicited after trauma in identified. Be aware that the staff and providers in the practice can also be impacted and also need support and education.

Decide how best to begin, but do begin. NJAAP is available to discuss next steps with any practice considering such change.

Trauma-Informed Care Resources:

- **Connected Kids:**

- **SWYC:**

- **Parent Screening Questionnaire (PSQ):**

- **Pediatric Symptom Checklist (PSC, PSC-Y)**

- **AAP Trauma Toolbox:**

- **Pediatric Psychiatry Collaborative (NJAAP):**
  www.njaap.org/programs/mental-health/

- **Family Success Center:**
  http://www.nj.gov/dcf/families/support/success/

- **Central Intake Agency:**
  www.nj.gov/dcf/families/early/visitation/Central%20Intake%20Sites%20-%20DOH_DCF.pdf

- **The Sanctuary Model:**
  http://www.sanctuaryweb.com/TheSanctuaryModel.aspx

References

1. SAMHSA's Concept of Trauma and Guidance for a Trauma-Informed Approach. July 2014
2. CDC Facts at a Glance, Child Maltreatment 2014

CME Quiz on page 17
CME Quiz

1. How many referrals does Child Protective Services receive each year?
   a. 500,000
   b. 1.5 million
   c. 3.5 million
   d. 5 million

2. The following are examples of Adverse Childhood Experiences (ACEs):
   a. abuse and/or neglect
   b. economic hardship
   c. parental/guardian domestic violence, divorce or separation
   d. Parental/guardian mental illness or incarceration
   e. All of the above

3. The Survey of Wellbeing of Young Children can be used for children ages 2 months–66 months:
   a. True
   b. False

4. Using the Adverse Childhood Experiences screening with parents can be a useful tool in primary care for eliciting origins of trauma and helping parents not repeat the cycle of neglect, abuse, and an authoritarian parenting style with their own children:
   a. True
   b. False

5. A recent study of a general family practice using the ACEs screen found the following _____% of families reporting at least 1 ACE:
   a. 16%
   b. 34%
   c. 62%
   d. 79%

6. An essential first step in being more trauma informed as a practice involves recognizing the large numbers of children and families in the practice that are impacted by trauma, and seeing the child’s and family’s issues and behaviors in the context of coping strategies developed to survive such adversity:
   a. True
   b. False

7. Having a proactive stance toward trauma-informed care in a practice involves which of the following?
   a. Including trauma in anticipatory guidance
   b. Screening for mental/behavioral health issues and trauma
   c. Creating a safe environment to prevent re-traumatization
   d. Realizing that engagement with families can trigger staff’s own trauma histories to reemerge or impact them negatively due to vicarious trauma
   e. Ensuring that families feel empowered in their own care decisions and care management
   f. All of the above

8. Basics of creating a safe environment for children, adolescents, and families includes which of the following?
   a. A physical space that is well lit, secure, with positive welcome signage and moderate noise levels
   b. Staff that are welcoming and engaging, and make families feel respected
   c. Posters and materials that are only in English
   d. Staff trained in cultural competency, especially with regard to how cultural mores impact perceptions of trauma, safety, and privacy
   e. a, b, and d.

9. Including aspects of trauma prevention into the anticipatory guidance content for well infant and child visits involves:
   a. Helping to educate families about positive parenting practices and positive discipline to ensure supportive attachment and bonding
   b. Focusing on acknowledging and building upon families’ resilience and strengths
   c. Having posters and parent education materials promoting such themes and practices
   d. Staff who are all aware of community resources

10. The Pediatric Psychiatry Collaborative is currently operating in 11 counties in NJ, and will soon spread to an additional 9 counties, offering consultative support for pediatricians who have patients with mental/behavioral health issues, and referral services for children/adolescents and families to access in their community:
   a. True
   b. False

CME Instructions

Read the CME-designated article and answer the Fall issue, quiz questions above. Print your name and phone number and mail or fax this form within six months from the date of issue to: NJAAP CME Quiz, 50 Millstone Road, Building 200, Suite 130, East Windsor, NJ 08520 Fax: 609.842.0015

NAME
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Submitter must answer 8 of the 10 questions correctly to qualify for CME credit

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This activity has been planned and implemented in accordance with the accreditation requirements and policies of the Medical Society of New Jersey through the joint providership of Atlantic Health System and the New Jersey Chapter, American Academy of Pediatrics. Atlantic Health System is accredited by the Medical Society of New Jersey to provide continuing medical education for physicians. Atlantic Health System designates this live activity for a maximum of 1.0 MA PRA Category 1 Credits™. Physicians should claim only the credit commensurate with the extent of their participation in the activity.
As this column is being written, summer’s end is at hand and we are about to begin the fall legislative session. As is customary for the New Jersey Legislature at this time of the year, there were only a handful of meetings through the summer. And given that 2017 is an election year, we don’t expect any significant legislative activity until after Election Day.

On November 7, 2017, New Jerseyans will be casting votes to elect a new Governor and Legislature. The Democratic candidate is former Ambassador, Philip Murphy who chose former Assembly Speaker, Shelia Oliver to be his running mate. The Republican candidate is Lieutenant Governor Kim Guadagno who selected Woodcliff Lake Mayor, Carlos Rendo to be her running mate.

Over the summer Governor Christie signed a number of bills including the following:

- **S291** authorizes health care providers, including, but not limited to, licensed physicians, nurses, nurse practitioners, psychologists, psychiatrists, clinical social workers, physician assistants, professional counselors, respiratory therapists, speech pathologists, audiologists and optometrists, to remotely provide health care services through the use of telemedicine and telehealth.

- **S1458** will require the Department of Health, in consultation with the Department of Banking and Insurance, to prepare informational literature on health insurance coverage for newborn children and make that information available to health care professionals who provide prenatal care. Every health care professional who provides prenatal care will be required to provide this information to new parents.

- **S359** raises the minimum age for the purchase and sale of tobacco products and electronic smoking devices from 19 to 21.

- **S2348** amends current law to provide that students participating in intramural sports programs organized by a public or nonpublic school will be included in the student athlete head injury safety program currently required for students participating in interscholastic sports programs, and that the coaches of intramural sports programs must also complete the safety training program.

In anticipation of the fall legislative session, representatives of the Chapter met with Senator Patrick Diegnan to discuss his bill, **S3086**. As introduced, the bill proposes three significant changes to current law. Current law permits pharmacists to administer the flu vaccine to children 7 and under. For children under the age of 12, the pharmacist may only administer the flu vaccine pursuant to a prescription by an authorized prescriber. This bill lowers the age for which a prescription is required from 12 to 10. The bill allows pharmacy interns and externs to administer the flu vaccine in the same manner as pharmacists. The bill permits pharmacists, pharmacy interns and pharmacy externs, pursuant to an authorized prescriber’s standing order, to administer any vaccine recommended by the Advisory Committee on Immunization Practices in the current “Recommended Immunization Schedule for Persons Aged 0 through 18 years” to a patient who is three years of age or older.

As a result of our discussion, Senator Diegnan agreed to delete the language in the bill that would have permitted pharmacists to administer all vaccines to children. He also agreed to clarify that pharmacy interns and externs administering the flu vaccine must be properly trained and supervised by licensed pharmacists when administering the flu vaccine to children.

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### Spend Much Time Addressing Vaccine Hesitancy?

The New Jersey Immunization Network Presents:

**Approaching the Vaccine Hesitant Parent Using C.A.S.E.**

**SAVE THE DATE**

This one-hour Webinar will air live
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Visit www.immunizenj.com to learn more
Pediatric practices across the state have seen an increase in audits from both commercial insurance companies and Medicaid. While some audits are routine and pursuant to provider agreements, others could expose practices civilly and criminally. In order to properly triage an audit and determine how to address it, it is recommended that every practice engage in some preventative medicine and have the following tools at their disposal.

**Practice Policies and Procedures**

Every practice has an employee manual, but how many of them have practice policies and procedures to address an audit? A practice should designate someone as the audit contact person for all audit and document request letters. Many times audit letters are ignored or not given the proper importance, which leads to unfavorable findings and large overpayment demands.

A practice’s audit contact person should take the time to read through an audit letter to determine three (3) key elements:

1. **Who sent the letter?** Is it from a private insurer, the Medicaid Fraud Division or another entity? Knowing who sent the letter is important to determining whether the audit is routine or potentially carries with it civil or criminal exposure.

2. **What is being requested?** Typically, routine audits only request a small amount of charts to “spot check” them, while targeted audits will request > 50 charts and focus on specific codes, modifiers or procedures.

3. **Why is the practice receiving this letter?** Many times, the purpose of the audit is stated on the letter and will point to “billing aberrancies” or “suspicion of fraud,” among other reasons. Determine the purpose of the audit and respond accordingly.

If the audit appears to be routine in nature, prepare all documents responsive to the request and keep an identical copy for your records. Note that sometimes you may need to send more than just the date of service being requested to support a code that is under review (e.g., accompanying printout of an audiology test for audiology codes).

In the event the audit contact person at your practice determines that the audit letter signals a looming overpayment demand or that it could lead to some exposure, notify your insurance company immediately. Many New Jersey medical malpractice insurers offer audit defense coverage that pays for experts and healthcare counsel fees incurred in defense of an audit and/or overpayment demand.

**Certified Professional Coder**

Certified Professional Coders (“CPC”) are vital to a proper defense of an audit. A CPC will look at the findings of an audit and double check the insurance company’s findings. As coding is to a large degree subjective, particularly when it comes to Evaluation and Management (“E&M”) codes, many times an independent CPC will refute the findings of the insurance company’s reviewer.

A CPC is also vital to determining:

1. Whether the practice received credit for any applicable downcode;
2. Whether the practice received credit for a different applicable code; and
3. If the practice requires additional education on proper coding procedures going forward, if any errors are discovered.

Also, as part of any practice’s preventative medicine, a CPC should be hired to routinely conduct an audit of the practice’s internal auditors or billing company.

**Healthcare Counsel**

Not all audits require the intervention of an attorney. Routine audits can be handled internally and without the need to obtain legal counsel or experts. However, a specialist healthcare attorney should be contacted in the event of any of the following instances:

1. When an audit letter contains words like “billing aberrancies” or “fraud;”
2. When an audit findings letter has a high percentage error rate (> 60%) as same could lead to the practice being put on pre-payment audit;
3. When a practice is notified that it is on pre-payment audit;
4. When an audit letter comes from a RAC auditor, the Medicaid Fraud Division or the Office of the Insurance Fraud Prosecutor; and
5. When the practice receives a letter notifying them that an inspector will be showing up to the practice to practice more than 50 records on-site.

If a practice takes the time to engage in some preventative medicine and is prepared to respond to an audit, many of the common pitfalls that plague practices can be avoided and much of the stress and anxiety of going through an audit can be minimized.
The use of computed tomography (CT) has increased significantly over the past two decades. Current estimates reveal that more than 60 million CT scans are performed annually in the United States, including as many as 7 million on children. Although CT has evolved into an invaluable diagnostic tool, recent attention has focused on the potential for increased radiation exposure to children undergoing these scans, and its commonplace use has now become a public health concern. Unique physiologic considerations in children make them particularly vulnerable to the deleterious effects of ionizing radiation. Studies have documented that low-dose radiation in childhood carries a small but significant increase in the lifetime risk for fatal cancer. While no data exists specifically on the relationship between head CT scans in children and tumor development, one study on the use of pelvic/abdominal CT scans in children shows one death linked to cancer for every 1,000 to 1,200 scans performed. Our target is to reduce the number of head CT scans performed on children by 20 percent with the hopes of reducing the related cancer risk in children.

Minor head injuries occur commonly in children and adolescents. Approximately 50 percent of children who visit hospital emergency departments with a head injury are given CT scans—many of which may be unnecessary. Children are particularly susceptible to the effects of radiation for three reasons: first, because of the rapidly dividing cells in growing children; second, children have a longer lifetime during which radiation-related cancers may develop; and third, until recently, most CT scans were not performed in accordance with the American College of Radiology’s recommendations on pediatric dose reduction due to children’s the smaller size. This has resulted in children receiving a higher radiation dose per unit of tissue as compared to that of an adult for a given study.

In 2013 the Choosing Wisely Campaign of the American Academy of Pediatrics stated, “Computed tomography (CT) scans are not necessary in the immediate evaluation of minor head injuries; clinical observation and the Pediatric Emergency Care Applied Research Network (PECARN) criteria should be used to determine whether imaging is indicated.” A study done at University of California Davis Health System by Diana L. Miglioretti, MD found that reducing unnecessary scans and lowering the doses for the highest-dose scans could lower the overall lifetime risk of future imaging-related cancers by 62 percent. In 2014, scientists and other healthcare professionals wrote a commentary, “An Appeal for Safe and Appropriate Imaging of Children,” published in the Journal of Patient Safety. The authors proposed the following National Quality Forum-endorsed measures be used in accreditation of hospital or medical imaging facilities: The Right Exam

a. Exam minor head trauma imaging: use of the Pediatric Emergency Care Applied Research Network Clinical Prediction Rule (PECARN). Use of the PECARN Clinical Prediction Rule for minor head trauma has been shown to significantly reduce the number of CT scans yet identifies 100 percent of cases in which appropriate neurosurgical intervention is beneficial.

The Right Way

a. Have protocols in place to reduce dual-phase head and chest CT imaging.

The Right Radiation Dose

b. Use of size-specific pediatric CT imaging protocols.

In the fall of 2016, the NJHA Institute for Quality and Patient Safety, working with the New Jersey Council of Children’s Hospitals under NJHA’s Hospital Improvement Innovation Network (NJHIIIN), brought together 47 participating hospitals committed to reducing exposure to ionizing radiation in children by reducing the use of CT scans when not warranted. The Children’s Safe CT Imaging Collaborative started by running administrative discharge data for all New Jersey hospitals looking at rates of CT scans on children under the age of 17 presenting with minor head injuries (treated and released from emergency department) and found varying rates across hospitals. Additionally, data was collected from the New Jersey Hospital Discharge Data Collection System (NJHDDS) for all 71 acute care hospitals and transferred to a tornado graph for comparability.

continued on next page
The goal of the Safe CT Imaging Collaborative was to evaluate the usage of CT imaging at each participating hospital. ALL hospitals were asked to evaluate their present usage. Those hospitals doing better (low number of CT scans) than the median (middle point of the tornado graph) were asked to evaluate their current practice through policy and procedures to effectuate even better results through continued reduction in usage and share with the group their improvement strategies. For those hospitals that fell below the median (high number of CT scans), the goal was to reduce their percentage by 20 percent over the 12-month collaborative period through improved policies and procedures and also fostering best practice through webinar sessions, office hours and hospital-to-hospital engagement.

Measures currently being used include:

- Head CT scans in the emergency room (ED) on children treated and released from the emergency room for minor head injuries: total number of head CT scans over total number of ED visits based on specific ICD-9 and ICD-10 diagnostic codes;
- Tornado chart comparing all hospital bases on above criteria for 2015, 2016, 2017 Q1;
- Development and implementation of protocols for the ordering of CT scans;
- Development and implementation of a pediatric radiation dosing protocol for CT scans by early 2018.

NJDDCS measures have been updated to adjust for hospitals’ conversion from ICD-9 to ICD-10 coding. NJHIIN now uses the first available 12-month period as the new baseline, namely Q4 2015 – Q4 2016 or “FY2016.” From this baseline through the latest available quarter (Q1 2017), avoidable pediatric head CT scans have decreased by 25 percent, translating to 956 avoided head CT scans.

The #ScanSmart Toolkit

The NJHIIN has turned its focus on patient education by developing informative materials for educating the public. The #ScanSmart toolkit will consist of pamphlets and posters highlighting the risks and benefits of CT imaging, and ionizing radiation, so parents, coaches, trainers, and others are better informed to comply with the recommendation of the medical staff. We hope to launch our CT Safe Imaging Toolkit by mid-September in time for children heading back to school and fall sports. The release will be supported by media outreach and social media messaging to further increase awareness.

NJHIIN will continue to promote the reduction of the number of head CT scans in children ages 17 and under, in an efforts to circumvent undue exposure to radiation. We are committed to providing our hospitals with the education and resources needed to continue to improve on their rate of CT imaging versus observation when warranted. We encourage all providers and members to take the Image Gently Pledge https://radsociety.wufoo.com/forms/image-gently-pledge/. #SCANSMART

References

7. Kuppermann, Holmes, & Dayan, 2009
Dry Drowning: Debunking the Myth

Putheenadam Radhakrishnan MD MPH FAAP
Bellevue Pediatrics, Pediatric ER Physician, Capital Health-Hopewell (Envision Physician Services)

Arvind Radhakrishnan MS1, Medical Student, St. Georges University, Grenada
Laila Adams PA-S, Philadelphia College of Osteopathic Medicine

Abstract

Recently, the term “dry drowning” has been making the rounds through numerous traditional and social media channels. And despite not being a factual medical condition, it has led to a ground swell of concern among families with young children.

According to the World Health Organization (WHO), drowning is “the process of experiencing respiratory impairment from submersion/immersion in liquid; outcomes are classified as death, morbidity, and no morbidity.” This definition encompasses all known cases of drowning incidents. Contrary to the misinformation that is troubling caregivers (and some physicians), there have been no documented cases of a patient that has deteriorated and died after exhibiting no symptoms at evaluation. Attention to this misdirected concern diverts the public’s attention away from focusing on the real danger to children, which is drowning.

Drowning is the second leading cause of unintentional death in children 1-14 years old. Pediatricians can help reduce the occurrence of death and disability from drowning by providing caregivers and patients with anticipatory guidance and education on avoiding risks and recognizing the symptoms of respiratory impairment that can result from submersion/immersion in water.

It is important to understand that there are only three scenarios for outcomes in drowning:

1. Fatal drowning resulting in death of the victim
2. Non Fatal Drowning with subsequent disability, injury or illness
3. Non Fatal Drowning with no injury or illness and complete recovery

Introduction

Driven by local and national media attention to dry drowning, caregivers have been reaching out to their medical providers seeking information and guidance on this worrisome condition. Chances are that when you hear the term “dry drowning”, the first thing that comes to mind is “Why have I not heard or learned about this condition?” The reason is simple: there are no medically accepted conditions classified as “dry drowning”, “near-drowning” or “secondary drowning”; there is only drowning.2 The term “dry drowning” has become problematic both because of its use in the general media as well as an occasional reference in some medical literature.

A quick internet search reveals numerous websites that address “dry drowning”. However, a cursory review of these pages uncovers the differences between the reliable and non-reliable sources of information. Web MD3, Wikipedia, and the WHO1 state that the term is not medically recognized. It is the non-medical sites (and some news organizations) that tend to infer that the term is a medically recognized condition, likely in an attempt to increase audience size. Again, while it is not a medical condition, “dry drowning” has been described to the public as a fatal drowning incident in which the victim “did not have any water in his lungs.” The explanation often provided for “dry drowning” is that laryngospasm occurs due to the influx of water into the trachea, which then leads to death even though no water was present in the patient’s lungs. However, contrary to non-medical media portrayals, patients cited as having died from “dry drowning”, have in fact, had a small amount of water in their lungs, demonstrating the real cause of death was drowning.1

Drowning Statistics

- According to the CDC, roughly 10 people die from drowning on a daily basis, and even more receive emergency department care for nonfatal drowning.4 Drownings make up 0.1 percent of injury-related emergency department visits.5
- For children ages 1-4, drowning surpasses motor vehicle accidents as the most common injury-related cause of death at 2.6 per 100,000 persons per year.6
- For children under the age of 4, drowning is the most common injury-related cause of death and most commonly takes place in a swimming pool.7
- Approximately 4,000 drowning deaths occur in the United States and over 300,000 drowning deaths occur worldwide each year.7
- In children, a significant majority of the drowning deaths occur as a result of lack of supervision. In 2014 a retrospective study showed that 91% of pediatric deaths were attributed to a lack of adult supervision. The same study reported that 82% of immersion deaths occurred in children under the age of 4.8
- The American Family Physician’ article discusses in depth the pathophysiology of drowning and the evaluation and treatment of drowning victims.

Discussion

In support of debunking the notion of “dry drowning”, Dr. Seth Hawkins, an emergency medicine doctor affiliated with Catawba Valley Medical Center in North Carolina, stated: “There has never been a case documented in medical literature of a patient who received a clinical assessment, was initially without symptoms, and who later deteriorated and died. People who have drowned and have minimal symptoms will either get worse or better within two to three hours.”2
Nevertheless, patients experiencing respiratory symptoms following a drowning incident should always seek prompt medical attention. Signs and symptoms of drowning that may be cause for concern include: difficulty breathing, excessive coughing, foaming of, in, or around the mouth, or neurological deficits.

Conclusion: Education is the Key

In conclusion, there is only one definition for the term drowning and it covers all the various outcomes. Other terms including “dry drowning”, “secondary drowning”, and “delayed drowning” are not medically accepted terms and should never enter into the conversation.

The most beneficial action healthcare providers can take is to educate patients and their families on the realities of drowning. This includes describing the different outcomes of drowning (death, morbidity, and no morbidity), explaining the signs and symptoms following a drowning incident that signify the need for healthcare attention, sharing recommendations to prevent drownings from occurring, and lastly emphasizing that “dry drowning” is simply not a medically accepted diagnosis or condition.

A few examples of steps that can be taken to help prevent drowning from occurring include:

- Using proper life vests or “floaties”
- Parents should be constantly watching children near water
- Becoming CPR certified
- Being aware of the weather and rip currents if in open bodies of water
- Avoiding the use of alcohol around water
- Having barriers to water such as a fence that meets local and state pool safety requirements

Remember, drowning deaths do not occur in patients who are asymptomatic for days to weeks and then suddenly deteriorate. However, if a patient is asymptomatic for more than eight hours after a drowning incident, but continues to present unexplained ailments, alternative diagnosis should be considered. And lastly, when discussing drowning with patients, the media or anyone else in the general population, medical personnel should stick to medically defined terms, rather than creating or using terms that may sound appropriate, but in the end, do little more than confuse and mislead.

References

Abstract

Healthy sexual development is an important milestone for all adolescents, including those with developmental disabilities. Pediatricians have an important role assisting adolescents and their families successfully navigate the emotional and physical changes of puberty, including sexual and reproductive health. Previous studies have demonstrated that adolescents with chronic conditions and disabilities are as likely to be sexually active as their peers. The focus of this article is adolescents with autism spectrum disorder (ASD), as they often experience delayed development of social and emotional skills that may require additional education and support regarding puberty. Nonetheless, many of the covered principles and strategies are useful for all adolescents. Adolescents with ASD may not be aware of the social impact of poor hygiene. Pediatricians should initiate anticipatory guidance early for adolescents with ASD as they may require additional reinforcement of hygiene techniques and privacy. Adolescents with disabilities are at increased risk for sexual abuse. Thus, it is important to discuss with them appropriate public and private behaviors. Visual cues and social narratives may be helpful when discussing how certain private behaviors such as undressing, urinating, and touching private parts should be done in private places, such as bedrooms and bathrooms. Menstrual management should be considered based on patient preferences and reproductive goals if menstruation interferes with patient activities. Finally, by having discussions of healthy sexuality with adolescents with ASD and their families, pediatricians may help them form respectful interpersonal relationships and improve their reproductive health outcomes.

Abbreviations

<table>
<thead>
<tr>
<th>ABA</th>
<th>Applied Behavior Analysis</th>
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<tr>
<td>ASD</td>
<td>Autism Spectrum Disorder</td>
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<tr>
<td>BMI</td>
<td>Body Mass Index</td>
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<tr>
<td>COC</td>
<td>Combined Hormonal Contraception</td>
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<tr>
<td>HgbA1c</td>
<td>Hemoglobin A1c</td>
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<tr>
<td>EPI</td>
<td>Individualized Education Program</td>
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<tr>
<td>MCV</td>
<td>Mean Corpuscular Volume</td>
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<tr>
<td>MCHC</td>
<td>Mean Corpuscular Hemoglobin Concentration</td>
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<tr>
<td>PCOS</td>
<td>Polycystic Ovarian Syndrome</td>
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<tr>
<td>PT/PTT</td>
<td>Prothrombin Time/Partial Thromboplastin Time</td>
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Case 1 Presentation: SP

SP is a 17-year-old young man with ASD, mild intellectual disability, and severe receptive-expressive language disorder presents for an initial appointment with a developmental pediatrician. He has an IEP and receives occupational therapy, speech and language therapy, social skills training, and counseling through school. Since his last visit a year prior, SP has been seen by child and adolescent psychiatry for his repetitive obsessive and self-injurious behaviors. In screening questions completed by the patient and parents prior to visit (Table 1), his mother identified being concerned that he still had difficulty understanding what were appropriate public and private behaviors despite her best efforts. Specically, he touched his penis over his clothes several times while on the bus home from school and once during school while watching a movie. Of note, SP does not have an aide during transportation. SP’s mother has tried to educate him that he cannot touch his privates in public, but the behavior has continued.

### Table 1: Screening questions related to puberty and sexuality

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
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<tbody>
<tr>
<td>How old is your child?</td>
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<tr>
<td>Has your child had any concerns about periods?</td>
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<td></td>
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<tr>
<td>Has your daughter had a menstrual period?</td>
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<tr>
<td>If yes, is she experiencing any difficulties?</td>
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<tr>
<td>What does your child like to do in his/her free time?</td>
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<tr>
<td>How does your child go to the bathroom independently?</td>
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<tr>
<td>Any concerns about your child's sexuality?</td>
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<tr>
<td>How does your child communicate now?</td>
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<tr>
<td>Can your child go to the bathroom independently?</td>
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<tr>
<td>Do you have any concerns about how your child is mastering daily living skills? (e.g., feeding, bathing, dressing, picking out appropriate clothes, transportation, money)</td>
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<tr>
<td>Do you have any concerns about body and emotional changes during puberty?</td>
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<tr>
<td>For your daughter: Has your daughter had a menstrual period?</td>
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<tr>
<td>If yes, is she experiencing any difficulties? (e.g., heavy bleeding, period lasting more than 7 days, significant pain, behavioral/emotional difficulties when she has her period) Also, any concerns about your daughter managing her pad or tampon?</td>
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<tr>
<td>What does your child do to in his/her free time?</td>
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<tr>
<td>How does your child participate socially?</td>
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<tr>
<td>How does he/she have friends or prefer to be on his/her own?</td>
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<tr>
<td>Does he/she have trouble engaging appropriately?</td>
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<td></td>
</tr>
<tr>
<td>Does he/she participate in extracurricular activities? Have hobbies/interests?</td>
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Per SP’s mother, he mostly masturbates in his bedroom, sometimes when the door is open. She is concerned that he often masturbates twice daily, which she believes is too frequent. Hence, she has been trying to leave the door open overnight to discourage masturbation. She reports that SP has never suffered any injury from masturbation.

**Case 1 Discussion: Counseling regarding appropriate private and public behaviors and discussion of healthy sexuality**

Pediatricians should provide anticipatory guidance about healthy sexuality by either reviewing highlighted resources including Puberty and Adolescent Resource: A Guide for Parents of Adolescents with Autism Spectrum Disorder and Healthy Bodies: A Parent’s Guide on Puberty for Boys with Disabilities with families or providing websites with the option to return with any questions (Table 2). These resources also provide guidance on how to prepare adolescents for medical visits that include genitourinary exams as part of comprehensive physical examinations.

**Table 2: References for parents regarding puberty and healthy sexuality**

<table>
<thead>
<tr>
<th>Highlighted Resources</th>
<th>Toolskits</th>
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Such discussions should include SP in a developmentally appropriate way, and include confidential time between SP and the pediatrician. Given the mother’s concerns, the pediatrician should provide reassurance that twice daily masturbation is a healthy expression of sexuality especially when there are no associated injuries, and that the focus should be on appropriate behavior in terms of modesty. The family should develop a team approach in managing these behaviors, engaging the school staff and outpatient providers. The resources in Table 2 include visual cues to help reinforce that private areas are covered by underwear and that SP should only touch private areas in private places, including bedroom and home bathroom. Allowing SP to have private space with his door closed for masturbation may decrease this behavior in public.

In this case, SP often inappropriately engages in masturbation in public when he is undirected. Therefore, it may be helpful to have an aide to accompany SP while being transported to and from school and help engage him in other activities, redirect him if he does inappropriately touch private parts in public, and educate him about appropriate behaviors. Practical tips for decreasing inappropriate public behaviors include having the adolescent wear pants with a tight waistband and/or briefs. Finally, given that adolescents with ASD are at increased risk of nonconsensual sexual encounters, it is important to screen for abuse and discuss safety and prevention. Adolescents should be offered human papilloma vaccine series as well as sexually transmitted infection screening if sexually active.

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Case 2 Presentation: PP

PP is a 17-year-old young man with a history of ASD, receptive and expressive language disorder, and mild intellectual disability who presents for an annual physical exam. PP has attended special education programming and has an IEP. He is currently in a special education class with approximately ten children, one teacher and one aide, and receives speech therapy, occupational therapy, and vocational programming. PP uses language to communicate with others, but has difficulties reading social cues and understanding humor. Socially, PP has some friends at school, but does not engage with peers outside of school. PP has certain strong interests, such as watching movies and running track. However, PP was recently removed from the track team due to disputes about his running time based on his watch versus the official time. His parents relate that PP can sometimes become rigid. PP reports his mood is good, yet he becomes annoyed when he does not understand a joke. He showed a picture he drew with a small stick figure of himself in the middle of circles with an arrow going into the circle of “joke I don’t understand.” In the circles, PP wrote “frustration, judgmental, annoyed”, which is how he reports he feels when he does not understand a joke. He further explained that the circles around him leave him feeling trapped by these feelings. He denies homicidal and suicidal ideation, hallucinations, and self-injury. PP does not have significant behavioral difficulties or elopement. His parents report that he is good about showering daily and picking out his outfits for school. PP has difficulties with shaving, and is often reluctant to participate in this activity. PP states that he is too young to start thinking about dating, and denies ever holding hands or kissing, or ever being touched in a way that makes him uncomfortable.

Case 2 Discussion: Emotional and physical changes with puberty

In addition to counseling regarding sleep, regular physical activity, and nutrition, a pediatrician should provide anticipatory guidance about the physical and emotional changes associated with puberty. PP is interested in interacting with peers and has participated in certain extracurricular activities. Still, his rigidity in certain situations and difficulties managing social cues has affected his ability to engage appropriately. His resultant social isolation places PP at risk for decreased self-esteem, anxiety, and depression. Approximately 26% of adults with ASD are estimated to suffer from depression and 11-42% have an anxiety disorder.7 Importantly, anxiety and depressive symptoms may be exacerbated by ASD-related impairments that increase social isolation.8 Adolescents with ASD may not always be able to verbalize some of these concerns, but may instead be able to express themselves using other means of communication, such as drawing. It is essential to evaluate an adolescent’s mental health through formalized assessments.9 Treatment strategies should be multifaceted, including cognitive behavioral therapy and medical management of anxiety and depressive symptoms for certain adolescents, based upon the severity of symptoms and their effects on functioning.10 The school may also be engaged to find vocational, recreational, and social opportunities to improve quality of life and aid transitions to adult services.

Adolescents with ASD often struggle with completing certain hygiene tasks, such as shaving. For PP, it is unclear why he is struggling to master shaving independently, but it may be related to his difficulties with change and sensory sensitivities. Further, adolescents with ASD are less likely than their peers to perceive the social relevance of maintaining certain grooming rituals. During the visit, the family was encouraged to prioritize tasks and obtain support from school staff, occupational therapist, and behaviorist. Tasks are broken down into a series of smaller steps that are represented visually or via a checklist. These visual checklists may be utilized along with “hygiene kits” that include all the necessary objects for each task, e.g., a razor and shaving cream. School staff and other professionals may be engaged in developing these tools by including social stories, videos, and reinforcement systems and assess patients for any fine motor weaknesses or sensory sensitivities. The family may want to model behaviors and explore different shaving equipment. Often adolescents with ASD may begin with an electric shaver since it is generally easier to manage, yet there may be sensory considerations.

The goal is to ensure independent completion of daily hygiene tasks by the adolescent. It is important to promote healthy hygiene habits early, develop routines around these hygiene tasks, and use a team approach to prioritize tasks and develop skills. Helping adolescents become as independent as possible with self-care and intimate hygiene tasks may make them less vulnerable to abuse. Overall, adolescence is a complex time for individuals with ASD and other developmental disabilities that includes both mastering adaptive skill tasks and developing a positive self-esteem.

Case 3 Presentation: JJ

JJ is a 19-year-old obese young woman with ASD, moderate intellectual disability, severe receptive-expressive language disorder, and Polycystic Ovarian Syndrome (PCOS) who was referred to adolescent medicine for management of menorrhagia with associated severe anemia. JJ was initially referred to an endocrinologist approximately 1 year ago for frequent periods and was found to have elevated free testosterone, fulfilling Rotterdam criteria for PCOS with androgen excess, ovulatory dysfunction, and exclusion of other etiologies.11 She has a BMI of 31 and insulin resistance with an HgbA1c of 5.8. Her endocrinologist started her on metformin 1000mg twice daily.

JJ had menarche at age 9 years and her mother reports that her menses occur every 2-3 weeks and last 5 days. Her mother reports it is difficult to quantify how heavy JJ is bleeding since she wears diapers. This history is consistent with moderate flow, given the presence of clots and no overflow when diapers are changed every 4 hours.

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JJ has limited communication skills making it difficult to assess for other symptoms or pain, but she exhibits no syncope. On physical exam, JJ is pale with a normal heart rate and blood pressure, no evidence of orthostatic hypotension, and cold hands. Her genitourinary exam is notable for no blood in diaper. Her pubic hair is in Tanner V distribution, her vulva had no lesions or lacerations visible on inspection, no clitoromegaly, and her vagina is well estrogenized with no discharge.

Labs are notable for severe iron-deficiency anemia with hemoglobin 7.3gm/dL, hematocrit 25.7%, MCV 60.2fL, MCHC 28.3gm/dL, iron level 23mcg/dL, low 5% saturation, and elevated 457mcg/dL total iron binding capacity. Normal white blood cells 8.2 x 10^9/L and platelets 396 x 10^3/µL. No evidence of acquired bleeding diathesis with normal PT/PTT and negative screen for von Willebrand’s disease.

JJ had no estrogen contraindications and was started on the continuous combined hormonal contraception (COC) norgestimate 0.25mg- ethinylestradiol 35mcg with the plan to allow a withdrawal bleed once hemoglobin improved to above 11gm/dL. The mother agreed to the plan after a discussion of benefits and risks, including increased likelihood of thromboembolic event. Prescribed ferrous sulfate 325mg three times daily and a stool softener as needed.

Case 3 Discussion: Counseling regarding menstrual management

Pediatricians have an important role in encouraging parents to talk to their adolescent girls about menstruation using correct, developmentally appropriate language. Pediatricians should assess the menstrual cycle, including regularity and heaviness of bleeding, associated dysmenorrhea, and behavioral changes. For adolescent girls with ASD, it is especially important to emphasize that menstrual periods are private. Parents can put together a “hygiene kit” for her pads or tampons and coordinate with school staff. Adolescent girls should be encouraged to become as independent as possible in their self-care, particularly with intimate tasks such as changing sanitary pads.

For JJ, the severity of her anemia due to heavy periods in the context of hyperandrogenism with PCOS warrants medical management. COCs and lifestyle changes are first line treatment options for management of PCOS.11 Starting continuous COCs with JJ will improve her severe anemia by decreasing menstrual losses. Further, discussed options for menstrual suppression in the future, including levonorgestrel-releasing system 52mg, which is approved for bleeding indications/menorrhagia. Adolescents should be screened for sexual activity and involved in these discussions as much as is developmentally appropriate. Most states including New Jersey recognize the rights of an adolescent to give consent for confidential services including contraception, testing for sexually transmitted infections, and pregnancy care.12-13 Nonetheless, when the patient is cognitively impaired, the issue of consent is more complicated and may require discussion regarding legal guardianship around medical decision-making.1,4

Case 4: DF

DF is a 17-year-old young man with Down syndrome, intellectual disability with intelligence quotient of 42, and pervasive developmental disorder who presents for a sick visit due to rhinorrhea and fever. He uses limited verbalization, some signs and a tablet to facilitate communication. On examination, marks are noted on his forearm that represent places where DF has bitten himself. Beginning at a few months of age, DF was involved with Early Intervention and has continued in a special education setting. He was in an intensive one-to-one ABA-based program for about 9 years, and just transitioned to a new special education school using ABA techniques but with a focus on transition programming, including vocational and adaptive skills. Since beginning program 9 months ago, his mother reports he has exhibited increased behavioral difficulties, with increased elopement, agitation, noncompliance and aggression approximately three times per month at home, at school, and in the community. Behaviors may include punching his mother or strangers in the head when upset and aggression towards his teacher. These behaviors seem to occur when DF becomes agitated over a demand or change, but triggers cannot always be identified. DF’s mother can sometimes redirect or calm DF by touching him. DF has also exhibited increased stereotyped movements, including rocking and hand movements, particularly in the past month with no other additional stressors noted.

Case 4 Discussion: Behavioral difficulties and puberty

Behavioral difficulties, including aggression, self-injury, and elopement, are significant concerns as individuals with ASD and other developmental disabilities become adolescents and reach a mature size that can be more challenging for family and other caregivers to manage. At this point, the adolescent is at increased risk of causing harm to himself or others, and therefore it is essential that the behavior is better understood and appropriately managed. Communication difficulties may complicate the assessment. The clinician should thoroughly assess for any medical etiology of behavior change including evaluating for pain or infection. Further, seizure disorders should be on the differential given their higher prevalence in adolescents with ASD. Approximately 20-35% of individuals with ASD versus 1-2% of the general population will develop a seizure disorder.7 There is a bimodal distribution to the development of seizure disorder in individuals with ASD, first in early childhood and then in adolescence. The likelihood of seizure disorders increases when changes in behavior are accompanied by somnolence, loss of bladder or bowel control, and regression of normal development. For DF, it seems that increased behavioral difficulties and stereotyped and repetitive behaviors were associated with the stressor of changing schools. However, careful assessment for organic etiology is always appropriate.

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Medical Malpractice Insurance

$1M/$3M          $2M/$4M

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<th>Rate Tier</th>
<th>Mature Claims Made:</th>
<th>Occurrence:</th>
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Puberty and Sexuality Counseling (continued from page 27)

Children and adolescents with ASD exhibit a high rate of behavioral difficulties even compared to children with other developmental disabilities with 49-68% exhibiting any aggression and 49% reporting attempt to elope in recent studies. Assessment and treatment of these behaviors typically requires a multidisciplinary team approach, including school and outpatient providers, and possible medication management. The family should be encouraged to engage the school district and outpatient ABA providers to perform a Functional Behavioral Analysis to understand the triggers, behavior, and current management of the behavior and develop the most appropriate individualized behavioral management plan. Additionally, the National Autism Association Big Red Safety Box and Autism New Jersey Elopement Resource Guide (Table 2) provide helpful information for families about developing a family wandering emergency plan, including a first-responder profile form, identification cards, and a discussion of various location devices.

Conclusion

Adolescents with ASD and other developmental disabilities may have challenges with puberty due to deficits in communication, social interaction, integration of sensory input, and co-occurring mental health and behavioral issues. Pediatricians have an important role in providing anticipatory guidance to adolescents with and without developmental disabilities and their families regarding puberty and healthy sexuality. Pediatricians should assess if there are concerns regarding the physical and emotional changes associated with puberty, and discuss respectful relationships, healthy sexuality, and reproductive goals. Toward preventing abuse, pediatricians should guide adolescent patients and their families regarding appropriate touching of private parts as well as encourage development of early hygiene skills. Identified concerns often require a team approach with school staff, therapists, and other providers to build skills and decrease challenging behaviors. The New Jersey Governors Council has awarded grants to establish pilot medical home programs to provide comprehensive and coordinated care for adolescents and young adults with ASD. These programs allow for team-based evaluations of the complex and multifaceted needs of this population. Additionally, they provide opportunities to collaborate with pediatricians, strengthen linkages with community resources, and raise awareness of the needs of adolescents with ASD.

References

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Case Report: Ulceroglandular Tularemia in New Jersey

Kei Wong, MD  
Nancy Yacoub, DO  
M. Cecilia Di Pentima, MD, MPH  
Goryeb Children’s Hospital, Atlantic Health System  
Morristown Medical Center

Abstract

Francisella tularensis is a fastidious, aerobic, gram-negative coccobacillus commonly presenting as glandular and ulceroglandular tularemia. We describe the clinical presentation and course of a pediatric patient with the ulceroglandular type of tularemia in New Jersey.

Introduction

Tularemia, a highly infectious zoonosis, is found in a wide range of animal reservoir hosts throughout most areas of the northern hemisphere. Infection can be acquired when: handling or having been bitten by infected animals or ticks, inhalation of aerosolized organisms, or by ingesting contaminated meat. In the US, 90 to 154 cases of tularemia were reported yearly to the Centers for Disease Control and Prevention (CDC) between 2001 and 2010.

Case Presentation

A 7-year-old male, with no significant past medical history, presented with a history of fever and neck pain over the past 3 weeks. Initially diagnosed with Streptococcus pyogenes pharyngitis, the patient was treated with amoxicillin-clavulanic acid without improvement. A CT of the neck showed multiple enlarged right-sided cervical lymph nodes along the jugular chain, posterior neck and supraclavicular region (Figure 1). He was hospitalized for intravenous clindamycin for presumptive Staphylococcus aureus lymphadenitis and discharged on oral clindamycin pending Bartonella henselae titers. Upon follow-up, the patient was noted to have a 1 cm ulcer on his right hairline raising the possibility of tularemia. He was hospitalized for intravenous clindamycin for presumptive Staphylococcus aureus lymphadenitis and discharged on oral clindamycin pending Bartonella henselae titers. Upon follow-up, the patient was noted to have a 1 cm ulcer on his right hairline raising the possibility of tularemia. The patient was readmitted for tissue biopsy and intravenous antibiotic therapy. Ciprofloxacin was chosen in order to avoid gentamicin and allow home oral antibiotic therapy. Because of his young age, doxycycline was avoided. Fever resolved within 24 hours and patient was discharged home on oral ciprofloxacin.

Serum B. henselae titers and lymph node PCR were negative, and F. tularensis titers were positive (1:1280). Three weeks later, F. tularensis titers raised 4-fold to 1:5120. The patient continued treatment with oral ciprofloxacin, but developed tendonitis and antibiotic therapy was switched to oral doxycycline to avoid another hospitalization. He subsequently developed a suppurative at the site of the lymph node biopsy, requiring re-admission for surgical debridement and intravenous therapy with gentamicin to avoid prolonged treatment with doxycycline and the possibility of permanent staining of his teeth. He was treated with two additional weeks of gentamicin with complete resolution of his right cervical adenitis and full closure of the surgical wound.

Discussion

This case describes the challenges of the diagnosis and management of tularemia in pediatric patients. There are six major clinical syndromes associated with tularemia. The severity and clinical presentation seen in human infections varies depending on the portal of entry, virulence of the particular organism, and immune status of the host. The two most common forms of tularemia in children are ulceroglandular tularemia and glandular tularemia.

In areas of low prevalence, diagnosis of tularemia has to be differentiated from other more common etiologies of glandular and less commonly ulceroglandular infection including: S. aureus, S. pyogenes, B. henselae (cat scratch disease), Yersinia pestis (plague), Bacillus anthracis (anthrax), and Spirillum minus (spirillary rat bite fever).

Local signs of acquisition, such as cutaneous papule, ulcer, or regional lymphadenopathy, are important clues for diagnosis of tularemia. The most classic presentation, and a clue to the diagnosis, is ulceroglandular infection, which develops after direct inoculation in the skin from a tick bite. This form is characterized by an enlarging ulcer at the site of inoculation, massive regional lymphadenopathy that may suppurate, and flulike symptoms.

Diagnosis requires a high clinical index of suspicion and is confirmed by a 4-fold or greater change in serum antibody titers, isolation of the organism, or detection of DNA by polymerase chain reaction. Serology is the cornerstone of diagnosis in tularemia, since the culture requires special media and a level 3 biocontainment facility.
Early suspicions of tularemia are important because delayed treatment may result in prolonged morbidity, increased risk of complications, including suppuration of lymph nodes (most common), and mortality. Without treatment, ulceroglandular tularemia has a 3% to 6% mortality rate and the illness may be protracted in those who recover. In the United States, where the highly virulent *F. tularensis* subsp. *Tularensis* prevails, antibiotic treatment with streptomycin or gentamicin for 7–14 days is the drug of choice for the treatment of tularemia in children.

Although tularemia has been reported from every US state except Hawaii, it remains an uncommon infection, especially in New Jersey. A search of PubMed Medline identified 13 cases of tularemia reported to the Centers for Disease Control and Prevention (CDC) from New Jersey between 2005-2015.

References

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**Key Findings:**

**Evaluation of Critical Congenital Heart Defects Screening Using Pulse Oximetry in the Neonatal Intensive Care Unit**

A recent article in *Journal of Perinatology* evaluated the implementation of early screening for critical congenital heart defects (CCHD) using pulse oximetry in the neonatal intensive care unit (NICU). Screening using pulse oximetry has become a near-universal tool to aid in early identification of CCHD. Many states require screening of all infants irrespective of clinical status or setting, posing unique considerations for implementation in the NICU. As literature on CCHD screening in the NICU is limited, the results of this NJ-led evaluation represent a major contribution to the field. Twenty-one participating NICUs across five states performed screening at multiple time points using the NJ-recommended or AAP-endorsed algorithm and modified for those infants receiving oxygen at 24-48 hours. The objectives were to evaluate the feasibility and burden associated with 1) early timing options for screening and 2) exclusion of infants with a prenatal CHD diagnosis, echocardiography conducted before screening, or born at less than 28 weeks gestation from universal CCHD screening in the NICU.

**Main findings from this study:**

- Of 4120 infants with complete screens, 92% did not have prenatal diagnosis of a congenital heart defect or echocardiography conducted before the screening; 72% were not receiving oxygen at 24-48 hours and 56% were born >2500 grams.
- 68% had neither pre-identifying factor and were not on oxygen comprising a subgroup who may benefit from early screening.
- Overall fail rate was low (0.9%, n=37).
- No infant with unsuspected CCHD was identified by screening.
- One infant with a previously unsuspected CHD was identified by screening.
- Fail rates at 24-48 hours were significantly higher among infants:
  - On oxygen (2.1%) than on room air (0.7%).
  - Born <1000 grams and/or < 28 weeks not on oxygen (7.4% & 9.5%).
- False positive rates were low for infants not receiving oxygen at 24-48 hours (0.5%) and those screened after weaning (0.6%), yet higher among infants born <28 weeks (3.8%) screened at 24-48 hours.
- Unnecessary echocardiograms were minimal (0.2%).
- Low burden of implementation reported by nursing staff.

**Key Takeaway:** Given the majority of NICU infants were >2500 grams, not on oxygen, and not pre-identified for CCHD, systematic screening at 24-48 hours may be of benefit for early detection of CCHD with minimal burden.


**More Information:** to learn more about NJAAP's work with CCHD screening, please visit http://njaap.org/programs/critical-congenital-heart-defects/
Movement Disorders in Children with Developmental Disabilities

Roger Kurlan, MD
The Center for Neurological and Neurodevelopmental Health (CNNH)
Voorhees and Rutherford

Children with developmental disabilities, such as autism spectrum disorder, mental retardation and genetic diseases, often experience a variety of movement disorders that may be difficult to diagnose and to distinguish from normal movements of childhood. When present they are often disturbing or concerning to parents. This article will review such movement disorders, providing information on diagnosis, etiology and potential treatments.

Habits are repetitive, coordinated movements commonly seen in normal individuals particularly during periods of boredom, anxiety, self-consciousness, or fatigue. Some habits are considered to be a normal part of development, such as thumb sucking. Thumb sucking usually disappears by age 3-4 years, but it has been reported to occur in 30% of 12-year-olds, typically when they are tired. After age 9, thumb sucking is associated with emotional immaturity. Biting fingernails, pens or pencils is another common habit which is reported by 40-50% of adolescents. These actions are associated with stress and anxiety. Some habits, such as nose picking, are considered socially inappropriate. Other common habits include finger tapping or drumming, leg shaking, pushing up eyeglasses, nose rubbing, and hair twirling. Behavioral therapy can be used to reduce or eliminate bothersome and persistent habits. Note that an important factor in properly diagnosing childhood movement disorders is paying close attention to “the company it keeps”. Thus, a particular movement, say finger tapping, could represent a habit, a stereotypy, a tic or a compulsion in a given individual. Long duration of the movement in a person with mental retardation or autism suggests it is a stereotypy, coexistence of vocal tics would point to it being a motor tic, coexisting obsessions suggests it is a compulsion, and absence of any of these suggest it is a habit (see below).

Mannerisms are peculiar characteristic ways of performing a normal activity, such as an odd (e.g., wiggling, stork-like steps) gait, an unusual speech pattern, or movement flourishes. Mannerisms serve to attract attention to an individual and are typically associated with personality disorders or schizophrenia.

Stereotypies are coordinated, rhythmic, repetitive, patterned movements, postures or vocalizations that are carried out virtually the same way over and over again for prolonged periods of time. Like tics, they can be divided into simple and complex forms. Examples of simple stereotypies are body rocking, head nodding, finger flapping, and moaning. Walking in circles, standing/sitting, repetitive words or phrases would be considered complex stereotypies. Also, like tics stereotypies can be of motor or vocal types. Stereotypies are commonly associated with mental retardation, with one study showing them present in about one-third of institutionalized adults (rhythmic movements in 26%, posturing in 13% and object manipulation in 7%). Some stereotypies can be self-injurious, such as head banging, skin scratching or eye poking, particularly in individuals with intellectual disability. Stereotypies are also commonly seen in patients with autism. A particular type, hand knitting, wringing or washing-like movements, point to the autistic disorder Rett syndrome. Two opposing hypotheses have been presented to explain the occurrence of stereotypies, particularly in those with autism. One proposes that autism represents a type of sensory and social isolation and that stereotypies are attempts by the individual at self-stimulation (they are therefore sometimes referred to as “stims”). An alternative view is that the repetitive actions are attempts to filter out and decrease what is felt to be an overstimulating environment. The fact that stereotypies frequently occur in people with congenital blindness and deafness (noises in deaf children but not the blind) has been used to support the notion that they occur in the setting of sensory deprivation or perhaps represent a manifestation of inappropriate processing of external stimuli. Stereotypies are generally treated when they are self-injurious or otherwise disabling. Due to evidence of increased brain dopamine with stereotypies, dopamine receptor blockers (antipsychotics) and dopamine depletors (tetrabenazine and newer derivatives) can be used.

Compulsions are repetitive and seemingly purposeful behaviors that are often performed in response to obsessions, according to rules (ritualistic), or to ward off future harm or a dreaded event. Attempts are made to ignore, resist or suppress the behavior. When compulsions are disabling, the diagnosis obsessive-compulsive disorder (OCD) is applied. Common compulsions include checking, counting, ordering/lining up, perfectionism and hand washing. Compulsions have been linked to abnormalities in the basal ganglia of the brain and disturbed serotonin neurotransmission. Cognitive behavioral therapy, selective serotonin reuptake inhibitors and atypical antipsychotics are standard treatments; deep brain stimulation (usually involving the nucleus accumbens) is used in severe cases.

continued on next page
Tics are involuntary movements (motor tics) or sounds (vocal tics). Simple motor tics consist of quick twitches or jerks, such as eye blinking, facial movements, head jerks. Complex motor tics involve more complex or purposeful-looking movements, such as touching, tapping, hopping, skipping. Simple vocal tics are sounds and noises like throat clearing, grunting, coughing, humming, etc. When there is linguistic meaning to the utterances (syllables, words, phrases) they would be considered complex vocal tics. These may include obscene or socially inappropriate verbalizations (coprolalia), but this phenomenon is uncommon in patients with tics. The presence of chronic (present for at least 1 year) motor and vocal tics in the absence of a primary cause such as medication-induced or an underlying brain disease (e.g., head trauma, encephalitis) signifies a diagnosis of Tourette’s syndrome (TS). Tics are common in children with autism and mental retardation. In this circumstance, they are considered secondary to the primary brain disorder and the diagnosis of TS is not used. Since they commonly occur together, there is often an overlap between the phenomena of tics and compulsions (“compultics”; such as having to tap a certain number of times) and impulsiveness (“impultics”; such as kicking or punching someone or having an urge to touch a hot stove). These overlap symptoms typically require treatment aimed at both phenomena to gain full control. Disabling tics can be treated with habit reversal behavioral therapy, an alpha-agonist such as guanfacine and an antipsychotic drug (classical or atypical). Derivatives of tetrabenazine have recently become available and they show evidence of suppressing tics.

Children with brain developmental disorders, often with cerebral palsy, commonly experience the movement disorders athetosis (flowing, wriggling and twisting movements; athetoid cerebral palsy) or dystonia (slow twisting or tightening movements). Anticholinergic or muscle relaxing medications (e.g., baclofen) may be helpful, but local intramuscular injection of botulinum toxin has become the standard treatment.

Finally, it is important to consider the possibility that any observed involuntary movements might be side effects of medications prescribed for other purposes, particularly antipsychotics or antiemetic drugs. These include acute dystonia when the drugs are initiated and, usually with more chronic use, parkinsonism, tardive dyskinesia, and akathisia (motor restlessness often associated with pacing, getting up and down from chairs).

References

New CDC Zika Testing Guidelines

On July 24, 2017, CDC updated its testing guidance for pregnant women with possible exposure to Zika virus. The update incorporates what has been learned over the past year and aims to reduce misinterpretation of Zika test results for pregnant women. (Read the full MMWR update here or visit: https://www.cdc.gov/mmwr/volumes/66/07/mm6607a1.pdf)

These new recommendations have implications for the care and evaluation of infants with possible congenital Zika virus exposure and emphasize the need for pediatricians to ask about possible Zika exposure for every newborn.

The CDC hosted a webinar July 2017 to review these updates. To access archived slides & audio visit: https://emergency.cdc.gov/coca/calls/2017/callinfo_072717.asp (click on the ‘Call Materials’ tab).

See also new CDC fact sheets:

Note: The New Jersey Department of Health (NJDOH) has created a new, updated Zika Delivery Packet for New Jersey Birthing hospitals. This packet serves as a comprehensive guide for evaluating and testing Zika exposed mothers and their infants at the time of delivery and prior to hospital discharge. Visit: http://njaap.org/programs/zika/resources/ to download a copy.
Sometimes in life, things just seem to fall into place at just the right moment - almost serendipitously. As a fourth year medical student, I recall a conversation I had with an attending, expressing how much I’ve always wanted to participate in a global health trip, but that I was too nervous to go on my own. Well, as fate would have it, that attending was responsible for organizing medical missions to Kingston, Jamaica in support of an organization called Missionaries of the Poor. After learning that I could apply to join one of these Missions, I immediately jumped at the chance without any second thoughts or hesitations. As a result, I am proud to say that I have participated in this mission three years in a row, most recently during my Pediatric Residency at Jersey Shore University Medical School.

Missionaries of the Poor is a Catholic Mission based in Kingston, Jamaica that provides shelters and orphanages to adults and children, regardless of religion. Their missions are located in underprivileged towns and villages throughout the world, including the United States. Missionaries of the Poor care for those individuals who many communities refer to as “throw-aways.” These are the misfortunate with mental and physical disabilities that communities are either unable or unwilling to provide support or needed care. These Missionaires, operating with extremely limited resources, provide the clothing, housing, meals, and medical care these vulnerable individuals require.

The children I am fortunate enough to care for in Jamaica have conditions ranging from mild autism and Down Syndrome to severe spastic cerebral palsy and heart failure. I also provide for children with a sequela of medication toxicity in utero and TORCH infections. Many of these children are born with these conditions and are left at the hospital by the parents, not because they don’t love them, but because they know they cannot afford to care for them. During my first trip to Jamaica, I recall walking into an open air room where children in their cribs formed a long line.

I remember thinking to myself, I was unprepared to handle the situation. It was so sad to see these children just lying in these cribs day after day after day. As I began to care for each child, performing their yearly physical exams, changing their medications to better control their seizures, and dressing their wounds. I quickly fell in love with each of them. It was the smallest things that brought joy—to them and to me. The slightest touch could quickly trigger an ear-to-ear smile and blowing bubbles could keep the more active children entertained for hours.

Words alone cannot properly portray the personal happiness and professional satisfaction and yes, occasionally, the sadness I have experienced during my trips to Jamaica over the past three years. I have seen maggot-infested wounds, a child with bronchiolitis who was turned away by the hospital system because she was “too sick for a bed” and the bed was needed for another child who had a better chance of survival. Mind you this child survived, mostly due to the love and support of a community who had very little to give, but possessed endless love and compassion. I have seen children with meningitis treated with amoxicillin, because that was all that was available. I have heard stories from local residents about day long waits in the Emergency Departments, and elevators being broken in the hospital so post-op patients had to take the stairs. Coming from a country, such as the United States, with vast resources, it seems almost incomprehensible to experience how others lacking these resources are living in our world.

As I being my PGY-3 year, I look back over my time as a Resident and know that my experiences in Jamaica have shaped me as a physician. Over the last three years, I have grown to call Kingston Jamaica, Missionaries of the Poor, and Bethlehem Home (the Orphanage that houses the children in Jamaica) my second home. Time spent working with few, if any, diagnostic tests, have helped me hone my diagnostic skills. This has resulted in making me think twice before ordering a test on a patient here at home. Sometimes I wonder if my work in Jamaica each year over has really made a difference for the children. However, I can say without hesitation, that the children I have cared for have and continue to make a huge impact on me, both as a physician and a person. As my return trip ends and the plane lands on US soil, I start counting down the days until I return to my Second Home.

Robin Craig, DO
PGY-3
Jersey Shore University Medical School

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Case Report: *Autoimmune Lymphoproliferative Syndrome Masquerading As Lymphoma*

Ajufo Ekene, MD General Pediatrics  
Ahmed Rafat, MD, Pediatric Hematologist/ Oncologist  
Children’s Regional Hospital at Cooper University Hospital

Abstract:

Autoimmune lymphoproliferative syndrome (ALPS) is a rare immune dysregulation disorder often mistaken for lymphoproliferative diseases such as leukemia or lymphoma, and thus, presents a significant diagnostic challenge. ALPS usually presents in childhood due to an inability to regulate lymphocyte homeostasis secondary to issues in lymphocyte apoptosis. These patients may present with nonmalignant lymphadenopathy, hepatomegaly, splenomegaly, as well as other autoimmune diseases.

We present the case of a 4-month old female, who was found to have splenomegaly during her well child visit. An ultrasound was obtained and confirmed splenomegaly. Her complete blood count showed thrombocytopenia with a platelet count of 60,000, and mild anemia. At 5 months, she was noted to be fussier, fatigued, having low grade fevers, and decreased oral intake. Her mother also noticed an acute enlargement of lymph nodes in the neck region.

At this point, the patient was admitted and Hematology/Oncology was consulted. Her peripheral smear was remarkable for lymphocytosis with few atypical lymphocytes, thrombocytopenia, and no other abnormal cells. After extensive oncologic workup, she was evaluated for lymphoproliferative disorder. She was diagnosed with ALPS based on flow cytometry results showing double negative T-cell population. She was started on 5 days of short-pulse prednisone and rapamycin. She continues her rapamycin maintenance therapy.

Case Description:

Our case describes a previously full-term 42-week gestation, now 5-month old, Hispanic female with no significant past medical history. She was incidentally noted to have splenomegaly and a low grade fever of 38.2°C at her 4-month well child visit. An ultrasound confirming splenomegaly was obtained and she was sent for blood work, which was remarkable for thrombocytopenia with platelet count of 60,000 along with mild anemia. The child continued experiencing fevers at home prior to hospital admission and was described as being more fussy than usual, fatigued, and had decreased oral intake. The patient was exposed to one sick contact at home with her 12-year old sister, who had been experiencing fever and chills. Mom denied any weight loss, hematuria, or melena. She acknowledged noticing two bruises on her infant’s back over the two days prior to admission, but denied easy bruising, bleeding or petechial lesions. The mother also reported enlargement of the lymph nodes of the neck during the two days just prior to admission and stated that her child had no exposure to lead or mold nor any history of travel outside of the United States.

Family History

The patient’s mother is a 45 year-old Hispanic female from Ecuador with a history of chronic anemia and previously treated Toxoplasmosis infection at the age of 3 years. She had enlarged lymph nodes and hepatosplenomegaly and underwent multiple surgeries. She has no history of epistaxis, gingival bleeding or menorrhagia, but does have a history of easy bruising, which was never investigated further.

The father is a 39 year old Hispanic male from Mexico with no history of chronic anemia, bleeding, or thrombosis.

Maternal aunt has a history of Lyme disease and Rheumatoid Arthritis.

The paternal side of the family history is generally benign.

The patient also had a maternal half-sibling who died at the age of 7 in Ecuador due to Histoplasmosis infection. She had hepatosplenomegaly at the time of her diagnosis.

Physical exam: Well-developed, well-nourished infant female with a strong cry. Unremarkable Cardiovascular, Pulmonary, Musculoskeletal, and Neurological exams. A 6cm mass from the angle of the right side of the jaw extending anteriorly into submandible area, it was tender to palpation, no erythema or induration or fluctuance. There is swelling with enlarged submandibular/parotid nodes on the left, but less than the right. Small axillary and inguinal nodes appreciated. Abdominal exam significant for diffuse tenderness without rebound or guarding, splenomegaly 4cm below the left costal margin, and hepatomegaly 5cm below the right costal margin at the mid-clavicular line. Skin was without rashes, pallor, or petechiae. A single bruise was noted on the left upper back.

Labs and Imaging:

**BMP:** Na 136 K 4.9 Cl 104 HCO3 18 BUN 10 Cr 0.2  
Glucose 114 Ca 9.2 AG 14

**CBC on Hospital Day #1:**  
WBC 16.1 (37% Neutrophils, 45% Lymphocytes, 17% Monocytes, 0% Eosinophils, 1%Basophils 1% atypical lymphocytes)  
ANC 6000  
Hgb 10.4 Hct 30.6 MCV 71 platelets 62,000

**CBC on Hospital Day #2:**  
WBC 8.3 (3% Neutrophils, 89% Lymphocytes, 5% Monocytes, 1% Eosinophils, 0% Basophils, 2% Atypical Lymphocytes)  
ANC 250  
Hgb 9.2 Hct 26.5 MCV 73 platelets 48,000

continued on next page
CBC on Hospital Day #3:
WBC 8.4 (1% Neutrophils, 84% Lymphocytes, 8% Monocytes, 0% Eosinophils, 0% Basophils, 7% Atypical Lymphocytes)
ANC 100
Hgb 9.5 Hct 28.8 MCV 72.7 platelets 59,000
LDH 838 unit/L
Uric acid 6.5 mg/dl
Direct bili 0, Total bili 8
UA:negative
Urine culture: no growth
Blood culture: no growth
HIV negative
Fungal cultures negative
Flow cytometry: granulocytes, lymphocytes and monocytes without diagnostic changes of leukemia or lymphoma.
Peripheral smear review: Normocytic, normochromic anemia, with mild microcytosis that could be related to physiological anemia or due to repeated blood draws. No nucleated red cells, no schistocytes, and no hemolysis.
WBC shows polymorphs with normal lobes, decreased in count with normal morphology.
Lymphocytosis with few atypical lymphocytes noted. No blasts and no other abnormal cells.
Monocytes appear normal with vacuolations, normal eosinophils.
Platelets show normal morphology but decreased in count.
Lymph node biopsy: Immunophenotypic findings consistent with T-cell lymphoproliferative disorder.
Ultrasound of the abdomen and neck: multiple enlarged lymph nodes in the right anterior neck. No drainable fluid collection. Persistent hepatosplenomegaly. Multiple periportal lymph nodes.

Hospital Course:
Our patient was admitted to the hospital for oncologic workup of her lymphadenopathy and worsening hepatosplenomegaly. She also underwent CT scan of the neck, chest, and abdomen. She was then taken to the operating room for lymph node biopsy and then she was discharged home. Two months later she presented to the Emergency Room with respiratory distress. Chest X-Ray showed prominence of the mediastinum and hila. She was transferred to an outside hospital for escalation of care. Flow cytometry at outside hospital showed a double negative T-cell population consistent with ALPS. Her genetic workup for known mutations was negative. She was started on a five day course of short-pulse prednisone and rapamycin due to lymphoproliferation without autoimmune cytopenias and discharged home on daily rapamycin. She continues to follow with her Hematology/Oncology and Genetics teams. Her autoimmune cytopenias have improved since initiation of immunotherapy.

Discussion:
This case report highlights a rare but important disease that can mimic lymphoma and leukemia in pediatric populations, particularly in infants. These patients are at higher risk for B-cell lymphomas later in life due to chronic multilineage cytopenias. The true incidence and prevalence of this disease remains unknown in part due to it being misdiagnosed or undiagnosed. It is interesting to note that although at this time no known genetic mutations have been identified in our patient, she has several female relatives who presented with hepatosplenomegaly attributed to other diseases, suggesting there may be an unidentified genetic mutation at play.

References:
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IMPROVE CHILDREN’S DIETS
with Nutrient-rich MILK

- Low-fat and fat-free milk are a good or excellent source of nine essential nutrients.
- Milk is the #1 food source of three of the four nutrients the 2015 Dietary Guidelines for Americans (DGA) identify as falling short in the diets of both children and adults – calcium, potassium and vitamin D.
- The DGA recommends low-fat or fat-free milk and milk products daily:
  - 3 cups for 9 years or older
  - 2 1/2 cups for 4-8 year olds
  - 2 cups for 2-3 year olds
- Milk is an integral part of school nutrition programs. Offering white or flavored milk with each school meal:
  - Provides important nutritional benefits to all, especially to the at-risk and food-insecure and
  - Helps students meet nutrition recommendations.

Visit nationaldairycouncil.org and dairygood.org
These health and wellness organizations recognize low-fat and fat-free milk as an integral part of child nutrition programs.

The United States Department of Agriculture (USDA) Summer Food Service Program (SFSP) ensures all children 18 and under have access to free, nutritious meals during the summer. The meals must meet USDA nutrition standards, which call for milk, fruits and vegetables, grains, and meat/meat alternates, and provide needed nutrition to children who may otherwise go hungry when school is not in session.

American Dairy Association North East teamed up with city officials and anti-hunger advocates and launched the FREE summer meals programs in Jersey City, Camden, and Paterson. “We know that the vast majority of our students rely on school meals during the academic year and that when school is out, hunger sets in for many of these children,” said Paterson Council President Ruby Cotton.

According to the USDA, only one in ten children eligible for free summer meals actually receives meals, leaving 19 million children unserved. When school is out, families can spend up to an additional $300 a month to feed children. The availability of free summer meals is vitally important to the health of children and helps stretch the food budget. “For many of our students, school meals are a key source of their daily nutrition,” said Dave Buchholz, Paterson Public School’s food service director. “Hunger does not take a summer break and neither should good nutrition.”

For more information on this year’s summer meals, visit http://www.dairyspot.com/summer-toolkit/, or contact Stacey Jackson, MS, RDN, CDN via email at sjackson@milk4u.org or by calling 315-481-6016.
If the answer to the following questions is yes...

- Has your practice experienced any difficulty connecting families to clinical psychologists and child & adolescent psychiatrists?
- Have your families expressed frustration over long delays in accessing mental/behavioral health services?
- Can your practice benefit from learning the best methods and strategies for screening, identifying, referring and care-managing children and adolescents with mental/behavioral health issues?

...The Pediatric Psychiatry Collaborative (PPC) can help

Provide access to a Child/Adolescent Psychiatrist for Diagnostic & Medication Consultations

Arrange an initial appointment with a Child/Adolescent Psychiatrist for urgent cases, regardless of family's insurance

Connect you with Psychologists and Licensed social workers to support care management and identify resources for children in your practice

In the early identification of mental/behavioral health concerns using standardized screening tools

Participants can also opt to join NJAAP’s ABP-Approved Maintenance of Certification (MOC) Part 4 Mental Health Program, aimed at helping pediatricians increase use of mental/behavioral health screening tools, anticipatory guidance, referrals and care coordination to support the early detection of mental/behavioral health issues, and the improvement of mental/behavioral health care in the primary care setting.

The PPC is expanding

Now, pediatricians in Bergen, Hudson, Hunterdon, Morris, Passaic, Somerset, Sussex, Union and Warren Counties are able to join the hundreds of pediatric providers already participating in this innovative program.

For more information on joining a regional Hub in your area, email: MHC@njaap.org, call 609.842.0014 or register online at: www.njaap.org/programs/mental-health/ppc