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FANNP NEWS

The Publication of the Florida Association of Neonatal Nurse Practitioners

Legislative Update Spring 2016

Ally Kayton, MSN, APRN, NNP-BC

I have exciting news about a policy initiative on behalf of neonates to share with all of you. Senate Bill (S. 2041 - The Promoting Lifesaving New Therapies for Neonates Act) that was introduced to the floor of the U.S. Senate by Senator Casey (D-Pennsylvania) and Senator Cassidy (R-Louisiana). I thought that the membership of NANN may be interested to know about the proposed Bill and possibly even lend its' support for passage.

This bill represents a bold, proactive initiative to spur and reward innovative research and development for neonates.

The bill would provide a one year, transferrable exclusivity extension to manufacturers who develop an innovative medicine specifically designed for the neonatal population. The additional one year exclusivity could be applied to any other approved product in the sponsor's portfolio or the sponsor could sell the exclusivity extension. By allowing for such an incentive, it is thought that this Bill will drive science-based new therapy development to target unmet medical need in the neonatal population, and, direct therapeutic development that is designed to address the unique physiologic needs of the population.

We are pleased to report strong bipartisan support

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Permanent Congenital Hearing Loss

Joanna McLaughlin, University of Florida

Introduction

Permanent congenital hearing loss (PCHL) is the most common birth defect in the United States. Infants hospitalized in the neonatal intensive care unit (NICU) have a higher incidence of hearing loss (5-35 per 1000 newborns) as compared to the general population (1-3 per 1000 live births), however, approximately 50% of infants with PCHL have no known risk factors, such as craniofacial abnormalities, congenital infections, NICU admission >2 days, syndromes associated with hearing loss, or family history of hereditary childhood hearing loss (United States Preventative Services Task Force [USPSTF], 2008). Even undetected mild or unilateral hearing loss may result in delayed speech, language acquisition issues, behavioral and social-emotional problems, and academic decline (American Speech, 2014). The purpose of this article is to review the guidelines set forth by the USPSTF for early hearing detection and intervention, to increase the NNP's knowledge on PCHL, and to encourage the NNP

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Letter from the President

Welcome to 2016, FANNP members!

With this being the first Newsletter of 2016, I have the privilege of reflecting on the accomplishments of 2015 and raise new excitement for the potential of 2016. The FANNP organization is filled with many passionate and dedicated NNPs. I would like to recognize the past FANNP Board of Directors and say thank you for a job well done. Moving forward as your 2016-2017 President, I plan to lead with commitment similar to those in the past and preserve the mission of the FANNP organization.

I have been a member of the FANNP organization since 1992 when I traveled to St. Pete to study for NNP boards. At the time, I lived in South Carolina, but immediately felt a connection with this exceptional organization. Being surrounded by fellow NNPs, I knew that this organization would play an important role in my career and my life. FANNP offered me a support network that appreciates my passion for the NNP role and gave me opportunities to develop my best practice. Since then, I have participated in FANNP as a member at large, assisted with conference committee, and now am honored to serve as your president. I currently practice in Orlando, Florida at Winnie Palmer Hospital for Women and Babies.

The FANNP organization continues to provide excellent opportunities for continuing education, including poster presentations, articles for newsletter, grants for research, and the FANNP conference. Our annual FANNP conference provides a unique, one-of-a-kind experience for Neonatal Nurse Practitioners; from student NNP board review to experienced NNP lectures providing cutting edge research in neonatology, the FANNP conference has something for every NNP at every stage of your career. The stunning venue is also the perfect backdrop for networking opportunities that give way to reunions, friends, relaxation and fun. I hope you'll join us this October!

FANNP is an organization founded by NNPs to serve the community of NNPs. FANNP members are educators at universities training our new colleagues. They are renowned lecturers in the field of Neonatology. They are representing the NNP role in state and national legislation. They are passionate about research in which they perform, analyze, and integrate their findings into new practices that affect our many NICU patients. They are working in NICUs across the country, making a difference in a unit near you! Whatever their role, this diverse group of NNPs is what makes FANNP an organization unlike any other. Therefore, continue your support as a FANNP member or perhaps challenge yourself to join in new positions that will be offered this year with the call for nominations. I'm looking forward to 2016, and hope to meet you all soon!

With many thanks for all the support,
Diana Morgan-Fuchs, NNP-BC
President, FANNP

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BRING IT ON ANSWERS

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1. Answer: B
The major determinant of fluid requirements for this gestational age is insensible water loss (IWL). A humidified incubator decreases those losses. It is physiologically and clinically important for a premature infant with RDS to contract the extracellular fluid space and remain in a slightly negative water balance. 80-100 mL/kg/day should achieve this goal. Without a humidified incubator the fluid requirement would be ~150 mL/kg/day.

2. Answer: A
The infant has a greater surface-to-body ratio. The infant's weight is 5% of the adult's, whereas its body surface is 15% of the adult's, increasing the surface-to-body ratio of the infant.

3. Answer: C
Profound sepsis produces shock and vasodilation that can increase heat loss and suppress the infant's normal homeothermic reactions.

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to continue their support of and collaboration with the audiology team to help facilitate early hearing detection and intervention in the vulnerable neonate.

Review

Benchmarks for PCHL evaluation and intervention are as follows: hearing screens should be done no later than one month of age, diagnostic evaluation no later than three months, and early intervention enrollment no later than six months (Joint Committee on Infant Hearing [JCIH], 2007). Studies have shown that automated auditory brainstem response (AABR) testing is feasible as early as a premature infant with a postmenstrual age of 30 weeks (Smets, Verrue, & Dhooge, 2012). It is appropriate for an NNP to be aware of potential hearing loss in neonates that have had severe birth asphyxia, hemodynamic instabilities, neurological disorders, exposures to aminoglycosides or other ototoxic medications, or high-frequency oscillator ventilation (van Dommelen, Mohangoo, Verkerk, van der Ploeg, van Straaten, 2010). A prudent NNP may also retest infants who have previously passed AABR testing if they have undergone any of the above-mentioned procedures, especially aminoglycoside administration (Smets et al., 2012).

Cost Effectiveness

According to the National Center for Hearing Assessment and Management (NCHAM), universal newborn hearing screening (UNHS) programs are "cost effective" and can cost $10-$50 per infant tested (NCHAM, 2010). Appropriating this cost to national PCHL incidence, each positive identification would cost less than $9,000. Today, children with PCHL are diagnosed at an average of two to three months of age, compared to prior to legislation, when children were diagnosed between two to three years of age. Timely detection of PCHL, combined with early intervention of services before the age of six months, will allow a child to having age appropriate communication outcomes by the time the child reaches first grade (Houston, Bradham, Munoz, & Guignard, 2011). Some sources have surmised that early intervention for PCHL can save over $1,000,000 in a child's lifetime, although research is not yet available to show absolute cost saving longevity (American Speech, 2014). In further support of the cost effectiveness of newborn hearing screening, the National Center for Hearing Assessment and Management (NCHAM) declares if only 2% of the "children identified with [newborn] hearing loss were educated in a non-residential program… [early intervention] would more than pay for the cost of the newborn hearing screening program in which all of the children were identified" (NCHAM, 2010).

Disadvantages of Universal Newborn Screening

There are two known controversial implications associated with UNHS. First, depending on the method of testing used, UNHS can yield up to a 30 percent false positive rate. However, this result can be significantly reduced to less than one percent by offering a two-step process, in which infants who test positive for hearing loss are tested twice prior to nursery discharge (Wrightson, 2007). Secondly, the potential increase in parental anxiety upon false positive UNHS may result. However, research has shown that lasting parental anxiety is minimal (MacNeil, Liu, Stone, & Farrell, 2007).

Potential Implications Related to Therapy After NICU Discharge

The integrity of UNHS program relies heavily upon timely post-discharge audiology provider follow-up of infants who originally tested positive for hearing loss. (USPSTF, 2008). Infants not routinely followed post-hospitalization are a major reason for failure to meet appropriate benchmarks. For example, one retrospective study in Indiana demonstrated that a considerable number of infants were not reaching the JCIH goals, 17% of infants were older than three months at initial evaluation, 18% of infants were lost to follow-up, and zero infants with PCHL received timely intervention, defined by amplification within one month of diagnosis (Krishnan, 2009). These identified gaps in care underscores UNHS purpose and the need for early intervention in a timely manner in accordance with JCIH, citing issues with checks and balance systems, and communication failures between the medical community, i.e. audiology and primary care providers. A SWOP (strengths, weaknesses, opportunities, and threats) analysis that surveyed 96% of national early hearing detection and intervention coordinators found that lack of follow up as the second most common weakness to the UNHS program (Houston et al., 2011).

Applicability to Bedside

It is important for neonatal nurses and advanced practice nurses to educate themselves regarding communicative approaches for the deaf and hard of hearing population. Families of infants diagnosed with PCHL require full and unbiased information to make informed decisions regarding early intervention, including suitable assistive hearing equipment, services, and programs that will work best for their family. These communication modality decisions are usually made in a short span of a few months upon discovery of the PCHL diagnosis of their child, as the JCIH benchmarks require intervention within one month of diagnosis (Gallagher, Easterbrooks, & Malone, 2006).

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Because 92% of infants with PCHL are born to hearing parents, these parents may have little to no knowledge on the topic, or their communication options (American Speech, 2014). Early intervention services include available pediatric types of hearing assistive technology such as hearing aids or cochlear implants, and communication options such as auditory-verbal, cued speech, English-based sign, or American Sign Language approach. Although information regarding hearing assistive technology is primarily presented by the audiologist, the family may turn to the neonatal provider for further questions or clarification, and a knowledgeable practitioner has the opportunity to support early intervention and the families' follow-up with audiology.

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Brag Board

Let's give a big kudos to Allyson Kayton, MSN, APRN, NNP-BC for being invited to speak at the Congressional Hearing in Washington, D.C. on February 22, 2016 regarding S. 2041 *Promoting Life Saving New Therapies for Neonates Act.* She proudly represented NANN and FANNP when speaking on the need for new innovation in neonatal drug therapies and research. The bipartisan bill has been put forth by Senator Bob Casey (D-PA) and Senator Bill Cassidy (R-LA). This bill would close the treatment gap by stimulating the development of safe, effective drugs for the neonatal population, and provide incentives to drug sponsors who successfully develop products for Neonates.

We are so proud of the work Ally has done in this area and so many other areas of our profession. She is a shining example to each of us. Congratulations, Ally!

For more information on the gap in innovation for Neonates and the Newborn Health Initiative, please visit www.newbornhealth.org.

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within the Senate Health, Education, Labor and Pensions (HELP) committee and broader Senate chamber. The goal will be to have the bill included as part of the Senate's "Healthier Americans Initiative" (companion to the House "21st Century Cures" effort), which is due out as early as late September.

Below is the link for you to write our senators, to encourage them to support this bill. http://thornrun.com/action-center/?vvsrc=%2fcampaigns%2f43803%2frespond

**** To find the mailing address, phone number, and/or e-mail address for your Senators, use the following Senate website for the most up-to-date information:* http://www.senate.gov/senators/contact/

FLORIDA UPDATE

2016 Legislative Session Outlook, Health Care Priorities

The Florida Legislature kicked off its 60-day session on January 12. The first two agenda items will likely be leadership priorities: water policy and job and educational opportunities for people with disabilities. Next on the list are education reforms and proposals for reducing health care costs.

Lawmakers are not expected to move on SB 856/HB 629, which would close the health coverage gap in Florida. The Florida Health Alliance is mobilizing Floridians to ask their representatives to at least debate the merits of SB 856/HB 629 (see below for how you can join us). The Alliance is also closely monitoring the following bills that are more likely to get traction this session. These bills may provide other ways to increase access to health care:

- Medical assistance funding through KidCare for lawfully-residing children (SB 248/HB 89), which would end the five year waiting period for children of legal immigrants to be eligible for the KidCare insurance program.
- Mental health and substance abuse (SB 12), which would implement a "no wrong door" model to optimize care, no matter where an individual enters the system. The bill would also require a plan for increasing the availability of federal Medicaid funding for behavioral health care.
- Scope of practice expansions (SB 152, SB 210, SB 676, HB 423), which would increase the responsibilities of Advanced Registered Nurse Practitioners and Physician Assistants, helping to ensure an adequate number of medical professionals are available to provide needed services.
- Nurse licensure compact (SB 1316/HB 1061), which would address the state's nursing shortage by allowing Florida to join 25 other states in a shared licensure agreement.

What is going on with APRN Legislation in Florida

As you know, there are several bills currently in play in both the Florida House and Senate that would authorize NPs to hold a DEA license and controlled substance prescriptive authority. Many of these bills contain slightly different provisions and may issue limitations on quantity prescribed or other aspects of prescriptive authority, but are a step forward and if passed in current form would make us the 50th state to grant NPs the authority to prescribe controlled substances.

Two of these bills are HB 423, by Representative Pigman, and SB 676, by Senator Grimsley. While these bills still have a little ways to go in the legislative process before they can be voted on in each chamber and have the opportunity to be signed into law by the governor, the following is what has occurred since the Legislative Session began:

January 15, 2015
Rep Pigman files DEA Bill HB 281
Was filed January 15th by Representative Cary Pigman MD. It adds ARNPs and Pas into Florida Statute 893 and would allow PAs and ARNPS to order DEA medications under supervision of a physician in a hospital. It also clarifies language for inpatient hospital care.

Senate Bill 0210 DEA prescribing bill filed.
Senator Denise Grimsley has filed S 0210 to allow NPs and PAs to obtain and use a DEA license in Florida. The bill has been referred to Health Policy, Banking and Insurance, and Rules Committees.

February 2, 2015
HB 547 Full Practice Authority Bill Introduced in House
HB 547 was introduced by Rep. Cary Pigman MD. This bill is a Full Practice Authority bill with some similar language as Senator Grimsley's DEA bill. HB 547 changes the term ARNP to APRN for Advanced Registered Nurse Practitioner, as in conformance with the National Council of State Boards of Nursing Consensus Model. It then adds

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a new category of INDEPENDENT APRN (IAPRN). An APRN can apply to become an IAPRN after 2000 hours of supervised practice by a physician within the last 3 years.

DEA Bill introduced in Senate
SB 614 was introduced today by Senator Denise Grimsley MBA RN and allows for ARNPS to obtain a DEA license.

Below is a press release from January 11, 2016 that may give these bills a boost:

LEGISLATION TO EXPAND AVAILABILITY OF MEDICAL CARE PASSES SENATE HEALTH POLICY COMMITTEE

Tallahassee — The Florida Senate Committee on Health Policy, chaired by Senator Aaron Bean (R-Fernandina Beach), today passed Senate Bill 676, Health Care, by Senator Denise Grimsley (R-Sebring). The legislation expands prescribing privileges for physician assistants (PAs) and advanced registered nurse practitioners (ARNPs).

"Florida is currently the only state that does not allow ARNPs to prescribe controlled substances and is one of two states that does not allow PAs to prescribe these medications," said Senate President Andy Gardiner (R-Orlando). "This legislation will help expand the availability of quality medical care by allowing skilled practitioners with advanced medical training to better meet the needs of their patients."

"There are many rural communities across our state where physicians are simply not available and patients with serious medical conditions have to travel great distances to receive care," said Senator Grimsley, a registered nurse with experience working in rural health care settings. "After completing years of education of clinical training, PAs and ARNPs have the skills needed to prescribe these medications to the patients they serve. This legislation will help make medical care more readily available while maintaining the high standards of training required to prescribe these controlled substances."

Senate Bill 676 authorizes PAs and ARNPs to prescribe controlled substances under current supervisory standards for PAs and protocols for ARNPs beginning January 1, 2017 and creates additional statutory parameters for their controlled substance prescribing. The bill requires PAs and ARNPs to complete biennial continuing education on the safe and effective prescribing of controlled substances.

Federal Legislation

The March of Dimes also sent a letter to the FDA on September 30, 2015 urging them to require both graphic warning labels and child-resistant packaging for liquid nicotine and other tobacco products, and to ensure that warnings sufficiently express the dangers of exposure to women who are or could become pregnant, as a means to protect these vulnerable populations. This would include novel tobacco products (often addressed as "other tobacco products" or OTPs) include dissolvables, which are flavored, smoke-free tobacco products that appear much like candy, and dissolve in the user's month.

As a reminder, 21st Century Cures Act is still going strong passing the House on July 10, 2015. The 21st Century Cures Act is a bipartisan bill that would reform the current standards and appropriations for biomedical research, provide $1.75 billion annually for the National Institutes of Health (NIH) and $110 million for the Food and Drug Administration (FDA). This funding would end after five years. Support for this funding would come from budget offsets. Along with an increase in NIH and FDA funding, the bill would reduce regulations on access to medical research and expedite the testing processes of new drugs. The bill was referred to the House Committee on Energy and Commerce, which released a section-by-section summary and a discussion document. The committee chairman, Rep. Fred Upton (R-MI6), sponsored the bill. It passed by a vote of 344-77. It received bipartisan support, with 170 Republicans and 174 Democrats voting in favor of the bill. It has moved on to the Senate.

MARCH OF DIMES LEGISLATIVE INITATIVES
The following March of Dimes Federal Priorities for the 114th Congress (2015-16), are:
- renewal of the Children's Health Insurance Program (CHIP) and
- promotion of funding for key federal maternal and child health initiatives.

Programs important to the March of Dimes include:
- CDC's National Center for Birth Defects and Developmental Disabilities and Safe Motherhood efforts;
- child health research at the NIH's National Institute for Child Health and Human Development and;
- HRSA's title V Maternal and Child Health Block Grant and newborn screening programs.

NATIONAL COUNCIL STATE BOARD OF NURSING

On Dec. 1, 2015 I attended the LACE meeting at ANA Headquarters in Washington, D.C. The discussions were very interesting and there is still work to be done. The 2015 deadline for the Consensus Model has come and the question is so now what? After much discussion, the decision was made "not" to re-open the consensus model. ANA and ANCC will be putting together a White Paper to discuss the Consensus Model. A draft should be sent out soon for review. I will continue to update our group as more information becomes available.

The most important "take-away"

is for APRNs to be registered in their state's Prescription Drug Monitoring Program; this will help in data collection, reviewing Schedule II prescribing patterns, and give us the data we need to counter the argument that APRNs prescribe more narcotics than physicians. Even if you don't write prescriptions, it is important to get registered.

Adding the updates since 2010, CNSs can now practice to the full extent of their education and training in 28 states and prescribe without a physician's supervision in 19 states. An additional 13 states allow CNSs to practice with the collaboration of a physician, and an additional 20 states have given CNSs the authority to prescribe drugs and durable medical equipment with the collaboration of a physician.

The review was done in consultation with NCSBN. Maps indicating states that have authorized CNSs full practice authority and independent prescribing authority are available through NACNS. NACNS commissioned the review to determine how much progress has been made since the publication of the Institute of Medicine report The Future of Nursing: Leading Change, Advancing Health, which recommended that nurses be able to practice to the full extent of their education and skills.

NCC Practice Update

Effective Jan. 1, 2016: All maintenance due dates are on the 15th of the month, instead of the end of the month. All individuals due to maintain NCC certification in 2016, 2017, 2018 or beyond have a new maintenance due date. This change affects all individuals holding an NCC credential, including RNC-E and those newly certified. NCC maintenance due dates are reflected in each individual's personal NCCwebsite.org account.

FANNP Scholarship Funds Available!

FANNP was founded to support the educational advancement of Neonatal Nurse Practitioners and remains committed to promoting education for NNPs.

Each year on December 31st, at least 10% of the available monies in the FANNP general operating budget are put in a scholarship fund.

FANNP is proud to be able to award scholarships to nurses and NNPs continuing their educational pursuits in the field of neonatal health care.

Two scholarships were awarded in 2015 to Joanna McLaughlin and Megan Glemza who are attending the DNP program at The University of Florida.

FANNP would like to be able to award more scholarships in 2016, but we can only award scholarships if we receive applications.

Are you, or is someone you know, eligible for a 2016 FANNP scholarship?

FANNP members who attend an educational program leading to a degree related to the health care field between September 15, 2015 and September 15, 2016 are eligible for a 2016 scholarship.

FANNP Scholarship Eligibility Criteria:

1. Scholarship applicants must be FANNP members.

- All members, student members and associate members are eligible.
- Priority for scholarship award will be given to members, followed by student members and then associate members.
- Priority for scholarship award will be based on length of membership and service to FANNP.

2. Scholarship applicants must be a licensed RN, ARNP, NNP or equivalent.

- Preference will be given to currently licensed certificate NNPs working towards a NNP degree.

3. Scholarship applicants must attend an educational program leading to a degree related to the health care field during the application period.

- Preference will be given to those working towards a degree in neonatal health care.
- The application period for the 2016 scholarship is September 15, 2015 to September 15, 2016. (i.e. To be eligible for a 2016 scholarship you must have attended classes sometime between September 15, 2015 and September 15, 2016.)
- An applicant may receive a maximum of two scholarship awards for each degree sought.

Applicants are asked to include a 3-5 page submission for publication in the FANNP newsletter as part of the application process. The submission can be an original article, a paper you submitted for coursework, a case study, best practice clinical update or a literature review.

The completed scholarship application packet must be postmarked by September 15, 2016.

For questions, more information or to obtain an application please contact FANNP via email at: scholarships@fannp.org.

FANNP's National Neonatal Nurse Practitioner Symposium: Clinical Update and Review, 2016

POSTER & PODIUM PRESENTATION
CALL FOR SUBMISSIONS

SUBMISSION DEADLINE: May 15, 2016

FANNP is seeking abstracts for posters and podium presentations for the annual FANNP's National Neonatal Nurse Practitioner Symposium on October 18th-22th, 2016. The planning committee invites submissions by members and non-members and participation is open to health professionals whose specialty has a focus on the Neonatal Population (this includes but is not limited to NNPs, RNs, Clinical Nurse Specialists, & Neonatologists). We invite colleagues to share their expertise in one of the following categories:

- Original Research
- Innovations in Practice or Education
- Patient Safety
- Quality Improvement and Benchmarking Initiatives
- Case Studies

PODIUM & POSTER PRESENTATION PEER REVIEW PROCESS
A panel of experts will choose the four best developed abstracts for a podium presentation. These will be selected on the basis of overall quality, originality and appropriateness to NNP practice. Preference will be given to research with complete data available. Podium presentations are 10 minutes with 5 minutes for questions. *Podium presenters will receive a $75 honorarium. All other conference expenses are the responsibility of the podium or poster presenter.

POSTER PRESENTATION
Abstracts not chosen for podium presentation will be considered for poster presentation. Detailed instructions for the poster presentation will be provided to the Primary Author at the time of the notification of abstract acceptance.

SUBMISSION REQUIREMENTS
Abstracts must be submitted electronically. Abstracts should be no longer than 500 words, in 12-point font, with up to 2 additional bibliography pages. The content should be presented in the form of a structured abstract:

- Purpose
- Subjects
- Design
- Methods
- Results
- Limitations
- Implications for Practice

A signed conflict of interest statement & CV (required for CE credits) must be submitted with the abstract. See the attached checklist for complete details. Abstracts that do not follow the submission guidelines will not be reviewed. Abstracts previously presented in other arenas are acceptable for submission. NOTE: Include the submission checklist with the abstract.

CONFERENCE EXPENSES: All presenters chosen for the podium and poster presentation are responsible for conference registration fees, travel and all other expenses.

Poster and Presentation Submission Forms are available on fannp.org

CALL FOR NOMINATIONS
FANNP Wants You!

This is an election year and positions are open for the Board of Directors for FANNP! The term of office is January 1, 2017 through December 31, 2019. All positions are a two-year commitment except for President-Elect. Responsibilities include attendance at Board of Director Meetings, participation at FANNP sponsored Symposium, and participation on established committees.

The Officer positions are:
President Elect: Fills in as President in their absence as designated, Chair of Bylaws Committee, succeeds to Presidency upon completion of term, and continues as Past-President following completion of Presidency term (4 yr commitment).

Secretary: Keep minutes of all meetings, gives notice of all meetings, keeps bylaws and membership records, responsible for email blasts and Chair of Communication Committee.

Treasurer: Have charge and full knowledge of all Association funds, render statement of financial condition of the Association for all meetings, and Chairs the Finance Committee.

Additional Board of Director Positions:
At-Large Members (4): Serves on committees as assigned.

*Please see website for a complete description of these positions.

To be eligible to run as an Officer, you must be a current member who has served on the Board of Directors or any FANNP committee. To be eligible to run for an At-Large Member position, you must be a current member with an interest in continuing the mission of FANNP.

Please consider running for one of these positions! We need your help to carry on!

Nominations are due by July 15, 2016. Send them to nominations@fannp.org. Ballots will be emailed to active members for voting by October 1, 2016. The newly elected candidates will be announced at the NNP Symposium Annual Member Brunch.

Thank you,
Leslie Parker, PhD, NNP-BC
Past President, Chair: Nominations Committee

POCKET NOTEBOOK

Diane McNerney DNP, NNP-BC

DiGeorge Syndrome Part 2

Recap

DiGeorge Syndrome (DGS), also known as 22q11 deletion syndrome, is caused by a defect on the long arm of chromosome 22.

Diagnostics

Genetic studies

- Chromosomal microarray analysis (CMA)
- Fluorescent in situ hybridization (FISH)
- TBX1 gene studies if microdeletion not detected via microarray, but suspected
- Multiplex ligation-dependent probe amplification (MLPA)

Additional laboratory studies

- CBC
- Serum calcium and parathyroid hormone (PTH)
- Evaluation of T-cell count and function via flow cytometry, reverse-transcriptase polymerase chain reaction (RT PCR) assay, and antibody response studies

Imaging studies to evaluate thymus and cardiovascular abnormalities

- Radiography
- Magnetic resonance imaging (MRI)
- Computed tomography (CT) scanning
- Echocardiography
- Angiography and magnetic resonance angiography (MRA)

Management

- Congenital heart defect repair
- Monitor and treat hypocalcemia
- Early thymus transplantation with complete absence of thymus (1% of DGS) or bone marrow transplantation
- Cleft palate repair
- Monitor for developmental delays, and refer to physical and speech therapy

Prognosis

DGS exhibits wide phenotypic variability. Prognosis is dependant upon the degree of various organ involvement, including cardiac, thymus and parathyroid gland, and renal. Death primarily secondary to cardiac defects, occurs in approximately 8% of cases. Many adults live long and productive lives.

Patient Education

Genetic counseling is essential to educate parents regarding the recurrence risk of 22q11.2 Deletion Syndrome. In addition, the families of patients with clinically significant immunodeficiency should be educated regarding the potential complications from exposure to live-attenuated vaccines. A reliable contact source of education is:

International 22q11.2 Deletion Syndrome Foundation Inc.
PO Box 2269
Cinnaminson, NJ 08077
http://rarediseases.org/organizations/international-22q11-2-deletion-syndrome-foundation-inc

References:

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2016 EDUCATIONAL OFFERINGS

Academy of Neonatal Nursing
13th National Advanced Practice Neonatal Nurses Conference
April 21-24, 2016
Sheraton Hotel and Marina
San Diego, CA
www.academyonline.org

Neonatology 2016
April 21-22, 2016
Emory Conference Center
Atlanta, GA
www.pediatrics.emory.edu/divisions/neonatology

Council of International Neonatal Nurses
9th Council of International Neonatal Nurses
August 14-17, 2016
The Westin Bayshore
Vancouver, Canada
www.COINN2016.neonatalcann.ca

Academy of Neonatal Nursing
16th National Neonatal Nurses Conference
September 7-10, 2016
Gaylord Opryland Hotel
Nashville, TN
www.academyonline.org

The Vermont Oxford Network Annual Quality Congress and Newborn Intensive Collaboration for Quality Symposium
October 6-9, 2016
Sheraton Chicago Hotel & Towers
Chicago, IL
www.vtoxford.org

The 26th FANNP Neonatal Nurse Practitioners Symposium: Clinical Update and Review
October 18-22, 2016
Sheraton Sand Key Resort
www.fannp.org

National Association of Neonatal Nurses
32nd Annual Education Conference
October 26-29, 2016
Renaissance Palm Springs and Palm Springs Convention Center
Palm Springs, CA
www.nann.org

CLASSIFIEDS

Classified Advertising in the FANNP Newsletter

Acceptance of Advertising

- Classified ads only
- Link on website for direct submission
- All advertisements are subject to review and approval by the Editor

Ad Options

- May run ad in one newsletter or all year- 4 total newsletters, December, March, June, and September issues

Cost

- $50.00/ad each newsletter or $150.00 for all 4 newsletters. No cash discounts.
- Payment must be received in full prior to the scheduled close date for the quarterly issue.
- Payments can be made though the PayPal link on the FANNP website

Format

- The classified ad section of the newsletter: will be limited to 1 page only with approximately 30 ads per page
- Ads will be processed on a first come first serve basis

Closing Dates for Space and Advertising Materials is as Follows

- Ad information and full payment must be received by the 2nd Friday in February to be included in the March newsletter
- Ad information and full payment must be received by the 2nd Friday in May to be included in the June newsletter
- Ad information and full payment must be received by the 2nd Friday in August to be included in the September newsletter
- Ad information and full payment must be received by the 2nd Friday in November to be included in the December newsletter

FANNP BOD

Bring it On...

Practice Questions to Prepare for the NNP Certification Exam

Answers on page 2

The December 2015 edition of Bring It On had incorrect answers. Correct answers are provided in this edition.

1. Baby S was born at 25 weeks EGA with a birth weight of 915 grams. He was placed in an incubator with 70% relative humidity. Which of the following rates of fluid administration would you choose initially for this infant?
   - A. 40-60 mL/kg/day
   - B. 80-100 mL/kg/day
   - C. 140-160 mL/kg/day

2. A full term infant has three to four times greater risk of heat loss when compared to an adult because:
   - A. The infant has greater surface-to-body ratio
   - B. The infant has a limited ability to sweat
   - C. The thermoregulatory ability of the infant is immature

3. Which of the following is felt to be associated with hypothermia in an infant with sepsis?
   - A. Immature response of the infant's immune system
   - B. Immaturity of the hypothalamus for thermoregulatory function
   - C. Shock and vasodilation with loss of homeothermic reactions

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