



Wednesday, January 29, 2025

8:00am – Teams

## MINUTES

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**CALL TO ORDER:** The Northeast Florida Pediatric Society (NEFPS) meeting was called to order on Wednesday, January 29, 2025 at 8:15am by Mark Bedard, MD, President.

**ADOPTION OF MINUTES:** The minutes of the October 30, 2024 NEFPS meeting were adopted as written.

**OLD BUSINESS** Dr. Bedard mentioned the last educational dinner presented by Dr. Kwong on January 22. It was well attended with plenty of good social time before and after the presentation.

**NEW BUSINESS** Dr. Sarandria shared information on the new 22Q Deletion Clinic. He is the medical director of the Snyder Cleft and Craniofacial Center which is completely funded by the Snyder family with assistance from community providers, dentists, orthodontists and maxillofacial surgeons that makes the services free to the patient. In conjunction with Dr. Trapane's Genetics Clinic, the 22q Deletion clinic will open May 15 and operate on a quarterly basis going forward. It is located on the 8<sup>th</sup> floor of the Pavilion Building on Prudential Avenue. Wolfson, Nemours and UF Infectious Disease are all onboard. Most cases from the Genetics Clinic will transition to the 22Q Deletion Clinic but referrals to genetics for genetic counseling or suspected additional issues is still encouraged. Dr. Jeffrey Goldhagen is the Clinic's Administrative Director, Megan O'Connor the program manager Sarah Fernandez, MD the surgical director and Catherine Swanson the 22q clinic coordinator. Help for telemedicine patients is available through Perfect Serve and there is a specific team there called "Cleft and Craniofacial team".  
**Note: the new clinic is just for 22Q 11.2 not for patients with 22Q duplications.**

22Q Deletion is a defective development of the pharyngeal pouch system causing choral trouble, cardiac anomalies, hypoplastic thymus, hypocalcemia due to parathyroid hypoplasia. It's possible to have any "constellation" of symptoms associated with this disorder. You could have one or all. Screening, usually done prenatally, for patients with a known deletion or a parent with a 50% risk of transmission, been identified at birth or prenatally with congenital heart disease, or advanced maternal age. The prenatal diagnosis can be made using chorionic villas sampling or amniocentesis depending on the age of the fetus. Then the preferred test is a chromosomal microarray, usually SNP array or legal plus or minus an SNP, the high risk HFMs. Postnatally the NICU will see a patient with heart disease (interrupted aortic arch, truncus arteriosus, TET, hypocalcemia, or poor oral intake. In toddlers and adolescence screening will continue, watching TSH levels, free T4, parathyroid

and calcium levels and some of these kids have palatal defects. Those with these defects, even if they've been repaired, will have issues with their ears, will need ear tubes, ear tube placement due to dysfunction of the Eustachian tube, and monitoring for speech and hearing problems. Their growth and development will need to be tracked closely. A lot of times they're referred for developmental delay, behavioral issues, psychosocial issues, bipolar disease, depression, or anxiety. In the first few years after birth, immune functions resulting from having no thymus there can still be cell issues so immunology usually needs to follow them.

The most common things seen with 22Q Deletion Syndrome:

Palatal anomalies in up to 100%

Speech delay in at least 69%. Intensive speech therapy is needed. If the patient has Velo Pharyngeal Insufficiency (VPI) they might need nasoendoscopy for diagnosis.

Other issues include:

Learning Disabilities

Cardiac Anomalies

Scoliosis

Dental problems

Skeletal abnormalities

Renal abnormalities

Currently these patients are being treated in multiple clinics, by multiple physicians, in northeast Florida. We have, unknowingly, had patients in our craniofacial clinic who have had multiple calcium levels in the same year with families not knowing that these same procedures are being performed by other physicians involved with their child's care. Due to the complex needs of patients with this syndrome, a multidisciplinary approach improves communication, deters overlap of screening labs and imaging, reduces healthcare costs, and provides a clear home for the families. Having central care and one EMR will be optimal for the patient and family. All the services needed to care for these children will be available on and in the vicinity of the Baptist campus Downtown. The institutional focus is on patient safety, patient outcomes, and quality.

**Dr. Reddy** expressed her excitement regarding the start of this comprehensive clinic. She mentioned a 15-year-old with Nayar Syndrome.

**Dr. Sarandria** responded that any craniofacial issues would continue to go to the same Snyder Clinic. The craniofacial clinic runs nearly every Thursday of the month. **Dr. Goldhagen** thanked Dr. Sarandria for his presentation and mentioned that developing this clinic was on Dr. Sarandria's list of priorities. The Snyder Cleft and Craniofacial Clinic has been in Jacksonville for decades. It operates under the auspices of the Partnership for Child Health and run as a collaboration between the private sector, WCH, UF, and Nemours. Services provided are everything from plastic surgery, ENT, speech, audiology, psychology, and social work. Contributions to the program has allowed growth that fosters the most sophisticated program in the state.

**STANDING** School Health Program: No report.  
**BUSINESS**

**FL Chapter - American Academy of Pediatrics (FCAAP) & FMA/CMS –Dr. Alissa** was called to another meeting. Dr. Rathore reported that the biggest concern is what's coming out of the CDC with immunizations. The FCAAP has sent out an advocacy update regarding this. Now is the time for NEFPS to gear up and pediatricians to be prepared for any issues that arise detrimental to patient care. We need to mitigate any damage or danger due to negative immunization reports and misinformation. Also, at present many of you are seeing patients with mycoplasma and RSV, some flu, not much COVID. **Dr. Alissa** returned to add: FCAAP retreat took place last weekend. Due to all the uncertainty and unknown currently, like the new administration freezing federal grants, a lot of progress couldn't be made at the meeting. Additionally, the confirmation of Robert Kennedy had not been approved. The plan was to push changes and improvements and to keep advocating. At this point if we can just maintain what we currently have that would be good. So, the focus is on Autism and reimbursement for physicians. Medicaid has reimbursement to diagnose and to perform and some evaluation testing for kids. Private insurance is not reimbursing so FCAAP is meeting with (ACA – what does this stand for?) and Sunshine. We will take what we learn to private insurance companies to see if they can reimburse their pediatricians for their time. We are

also wanting to prioritize school health and access to food for children in the state. They just had their first meeting in preparation for the 2025 legislative session focusing efforts to increase the pediatric subspecialty workforce, improving healthcare for children with publicly funded schools, including increased funding for school nurses and securing continuous Medicaid coverage through age 6. Dr. Alissa and Lisa Quinn, previous FCAAP president attended a DCF meeting regarding the submission a FL application for The Sandbox, credit for summer food. Unfortunately, the January deadline to apply was missed. However, now even if we had applied with the freezing of federal grants, it might not have happened anyway. A letter was brought late to her attention regarding breastfeeding. The letter warmly welcomes the new Congress and urge them to act on the sessions regarding it and priorities on infant nutrition, security and federal funding, family and medical leave, access to lactation support and supplies for maternity care practices. **NOTE: NEFPS joined and signed the letter online before the deadline.**

#### **AAP Report – No report**

#### **WCH – Dr. Mark Toney, Chief Medical Officer reported:**

- Congratulated Dr. Sarandria for all his efforts around the creation of the 22Q clinic.
- US News and World Report ranked WCH in four specialties – Neurology & Neurosurgery, Diabetes & Endocrinology, Cancer and Pediatric & Adolescent Behavioral Health, In December the Leap Frog Group rated WCH as a top Children's Hospital!
- Medical Errors – the commitment to decrease medical errors, hospital-acquired infections and conditions thanks go to our physician groups and team members for their successes.
- Florida Forum – the WCH Women's Board raised funds through two presentations by Dr. Deepak Chopra and Shad Khan. Last author Carl Hiassen, a Floridian and well-known author will present. The funds from the Forum will go to enhancing and complementing the Operation of Kids Care transportation for our patients.
- Nemours has made a significant addition to the ENT service decreasing wait times. Neurology has also had several additions. There has also been significant improvement for Anesthesia after the shortages over the past couple of years. Fellowship-Trained Anesthesiologists are providing needed services in the ORs and sedation.
- Outreach – a new business development specialist started in February. That person will be a designated liaison between everyone on this call and referring providers with WCH.
- New Pediatric ERs – St. Augustine opened at the end of last year and Nassau Crossing on the northside opened providing access to pediatric
- Specialty team members for acute visits there.

#### **University of Florida: No report**

#### **Nemours Children's Health (NCH) Update: Dr. Stec reported on the huge recruitment effort over the last six months.**

- It has added pulmonologists, neurologists, ENT physicians, GI physicians and orthopedic support staff, new HEM/ONC folks and a new endocrinologist. With the growth there's been a significant improvement with access for most subspecialties. One to two groups are still lagging but almost every group is seeing new patients in under 14 days.
- Aaron Carpenter, President-Nemours North FL Region, will start Monday, February 3.

- New Orthopedics Department Chair coming from Boston Children's in July with the aim of starting a world-renowned program in hip preservation.
- The search for a new Chair of Pediatrics is underway. There are several exciting candidates that have begun interviewing. We hope to have Dr. Chandler's replacement named by the end of Summer-early Fall.

**Dr. Rolle** asked about referrals to Nemours Neurology. They were told there was no pediatric neurologists available in the city. Dr. Stec answered that in the last six months three new neurologists were added to staff. One of them is starting in the next week or two and even with that there are available neurologists. There are also telehealth services for patients to be seen. During that lengthy period and with a dearth of neurologists some were having to wait three months.

**St. Vincent's Family Medicine Residency Program Update:** They have been approved for 12 residents per class versus the prior 10. Now in the second half of PGY 1 and their residents are active in the community. They are waiting for the MATCH and thankful for rotations thru WCH.

**Secretary –Treasurer's Report:** Dr. Osman noted that membership is up to 90-95. We had our first successful educational dinner last week that went well on a very cold evening. Our FACEBOOK Members-Only group page is up and running. She urged everyone to become a member and urged fellow pediatric doctors and AAPs at their practice to join and to spread the word about NEFPS.

There being no further business, the meeting was adjourned at about 9:12am. The next meeting of the Northeast Florida Pediatric Society will take place on Wednesday, April 30, 2025, at 8:00am via Teams.

Approved by: Mark Bedard, MD – NEFPS President