Pediatric Stroke Education and Training Initiative







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Pediatric Stroke Categories

Perinatal Stroke

Last 18 weeks of gestation through 1-month old



Michelle Hemorrhagic Stroke between 20 and 29 weeks gestation

No known cause for stroke

Childhood Stroke

1-month old to 18 years



Ryley Multiple Ischemic Strokes at age 15 Caused by bacterial infection

Pediatric Stroke Statistics

- There is no universal surveillance for this population
- There are no ICD-10 codes for any category of childhood stroke (not age specific)
- Some statistics we do have for the U.S. and Canada:
 - The prevalence of *Perinatal Stroke* is 1 in 4,000 live births (AHA 2019)
 - Incidence of *Perinatal Stroke* may be as high as 1 in 1,000 live births (Canada)
 - The annual incidence of *Childhood Stroke* ranges from 3 to 25 per 100,000 children (AHA 2019)
 - In Canada there are more than 10,000 children (0 18 years) living with stroke
 - The numbers we do have are thought to be lower than actual cases

Management of Stroke in Neonates and Children: A Scientific Statement From the American Heart Association/American Stroke Association <u>https://doi.org/10.1161/STR.000000000000183</u>Stroke. 2019;50:e51-e96 The Stroke Association/UK, "Childhood Stroke Fact Sheet", April 2012 edition. Heart and Stroke Foundation of Canada, "Different Strokes 2017 Stroke Report".

Pediatric Stroke Facts

- Stroke is one of the top 10 causes of death in children ages 1 19
- > Approximately 80% of *Perinatal Strokes* are Ischemic
- > About 50% of *Childhood Strokes* are Hemorrhagic
- Pediatric stroke is as common as brain tumors in kids
- Incidence of Childhood Stroke is highest in infants and children under 5 years-old
- For children, boys have a higher incidence rate than girls
- Black and Asian children have a higher incidence than white children
- Increased stroke risk in black children due to Sickle Cell Disease

Tsze DS, Valente JH. Pediatric Stroke: A Review. *Emergency Medicine International*. 2011; 2011: 734506 Management of Stroke in Neonates and Children: A Scientific Statement From the American Heart Association/American Stroke Association <u>https://doi.org/10.1161/STR.00000000000183</u>Stroke. 2019;50:e51-e96

Some Risk Factors for Pediatric Stroke

PERINATAL

- Cardiac disorders
- Coagulation disorders
- Infections
- Trauma
- Maternal placenta disorders
- Maternal medications and toxins

In most perinatal strokes, no risk factors are ever found

Overall risk for another stroke is extremely low, < 1%

CHILDHOOD

- Congenital heart disease
- Cardiac disorders (e.g. Myocarditis)
- Cerebral vascular disorders (e.g. Moyamoya, Arterial Dissection)
- Infections (e.g. Varicella, Meningitis)
- Head or neck trauma
- Sickle cell disease
- Autoimmune disorders

No previous risk factor is identified in about half of childhood stroke cases

After an initial stroke, ~20% will have a recurrent stroke

International Alliance for Pediatric Stroke & American Heart Association, "Strokes Can Happen at Any Age", 2014 infographic.

American Heart Association, "Youths and Cardiovascular Diseases, Statistical Fact Sheet 2015 Update".

University of North Carolina Comprehensive Stroke Center, "An Overview of Pediatric Stroke: Prenatal Through Teenager, An Educational Guide for Healthcare Providers", 2015 edition.

After a Pediatric Stroke

Of children surviving stroke, over 75% are left with permanent, long-term neurological deficits.

These include:

- Hemiplegia/Hemiparesis paralysis or weakness on one side of the body (most common deficit)
- Learning and memory problems
- Difficulty with speech and language
- Different types of impaired vision
- Behavioral or personality changes
- Development of epilepsy (not typically seen in adults)

Children's Hospital Cleveland Clinic, "Facts About Pediatric Stroke", September 2010.

Amlie-Lefond, Catherine. "Evaluation and Acute Management of Ischemic Stroke in Infants and Children." CONTINUUM: Lifelong Learning in Neurology, vol. 24, no. 1, 2018, pp. 150-170., doi:10.1212/con.00000000000559.

Signs and Symptoms for Perinatal Stroke

Newborns

- Seizures may be an early sign: repetitive twitching of face, arm or leg
- Apnea, especially associated with staring
- Lethargy, poor feeding

Developing Babies

- Decreased movement or weakness on one side of the body
- Showing a hand preference, or consistently reaching out with only one hand before <u>one</u> year of age

Solomon

Developmental delays

International Alliance for Pediatric Stroke & American Heart Association, "A Stroke Can Happen to Infants and Unborn Babies", 2017 Fact Sheet.

Delay in Diagnosing Perinatal Stroke

- Management of perinatal stroke problematic/signs are subtle
- No standardized early intervention exists
- First few years of life critical for activity-dependent plasticity
- 40% of cases are first detected outside neonatal period
- Symptoms may appear about 5 months after birth asymmetry
- 12.6 month average delay between parental concerns and final diagnosis

Delay in Diagnosing Perinatal Stroke







Avery Photo at 6 months Diagnosed at 11 months Dana Photo at 7 months Diagnosed at 19 months Brendon Photo at 8 months Diagnosed at 19 months

Signs and Symptoms for Childhood Stroke

Signs and symptoms of acute stroke in children are similar to those in adults (F.A.S.T.)

- Sudden <u>Hemiparesis/Hemifacial</u> weakness numbness/weakness on one side (67% to 90%)
- Sudden <u>Difficulty Speaking</u> or understanding others (20% to 50%)
- Sudden, severe <u>Headache</u> (20% to 50%)
- Sudden <u>Vision Loss</u> or double vision (10% to 15%)
- Sudden <u>Ataxia</u> loss of full control of body movements/coordination (8% to 10%)
- Sudden altered <u>Mental Status</u> (17% to 38%)
- Seizures at stroke onset are more common in children than adults (15% to 25%)

Management of Stroke in Neonates and Children: A Scientific Statement From the American Heart Association/American Stroke Association https://doi.org/10.1161/STR.000000000000183 Stroke. 2019;50:e51-e96

Delay in Diagnosing Strokes in Children

- Often unrecognized and untreated
 - Poor awareness of strokes in children among emergency physicians, frontline providers, and parents/caregivers
 - Symptoms mimic other diseases (e.g. migraine, seizures, Bell's Palsy)
- Accuracy and timeliness of diagnosis are important challenges
 - 1.7 to 21 hour delay from symptom onset to seeking medical help
 - 15 to 24 hour delay before brain imaging done
 - Delays in accessing MRI due to need for sedation/anesthesia
 - MRI delays greatest in evenings/weekends
 - Head CT often appear "normal" with ischemic stroke
 - ED providers correctly diagnose a stroke in 60% of children

North Carolina Pediatric Stroke Cases

Diego



- Age 13-months
- Learning to walk
- Typical toddler
- No health issues

- At home with parents
- Right arm suddenly went limp
- Couldn't stand up
- Parents recognized may be stroke
- Drove to hospital 30 min away
- Hospital ED assessment: dislocated shoulder, wanted to do x-ray
- Dad insisted on MRI
- Results of MRI showed ischemic stroke
- Hospital for a week
- Intensive therapy for one month
- No cause found for stroke

Annika



- Healthy 13-year-old
- Golf team
- Ran cross country
- Honor roll
- Had started Duke TIP program

- Headaches in May
- June unbearable headache, couldn't feel left side of body, slurring words
- Taken to ED Dr. thought symptoms were heat related or puberty, NOT STROKE
- Told to come back for outpatient MRI in a week
- 3rd day collapsed & rushed to Urgent Care
- Life flight to larger hospital—had suffered brain stem stroke (4 strokes total)
- Locked-In Syndrome for a month
- Transferred to hospital 3 hours from home for rehab, stayed for 3 months
- No cause found

Nazhai



- Age 16
- Dancer
- Active in her church
- In the high school business program

- At the pool on a hot afternoon
- Sudden, excruciating headache
- Right arm numb
- Slurred speech
- Couldn't stand up
- First Responders diagnosed as heat stroke and migraine
- Taken to the hospital an hour after EMS arrival
- No urgency for assessment, treatment or MRI upon arrival at hospital
- Treated for dehydration & migraine
- Results of MRI were given ~7 hours after hospital arrival
- 2 brain aneurysms/hemorrhagic stroke -12 hours after initial symptoms
- No cause found for aneurysms

Target Audiences for Pediatric Stroke Education and Training

- Emergency Medicine Physicians
- Paramedics
- Emergency Medical Technicians
- Nurses
- General Practitioners
- Pediatricians (perinatal stroke)
- School Nurses/Health Aides
- School Coaches
- Public Health Personnel



Implementation Plan

- Add a required Pediatric Stroke CME for all NC Nurses and MDs
- Include pediatric stroke in the Stroke Certified Registered Nurse (SCRN) Review Course curriculum (consult with MED-ED)
- Advise the American Heart Association (AHA) to add Pediatric Stroke signs and symptoms to Get With the Guidelines: Stroke for certification for Comprehensive and Primary Stroke Hospitals
- Advise the AHA to add Pediatric Stroke to the <u>Pediatric Emergency</u> <u>Assessment, Recognition and Stabilization</u> (PEARS) and <u>Pediatric Advanced</u> <u>Life Support</u> (PALS) training material
- Education seminars for statewide hospitals/medical centers/EMS
- Consider hosting a state-wide Pediatric Stroke conference for Medical Providers, Researchers, and Patients/Families
- Consider including pediatric stroke cases once the Hospital Survey project is complete to gather statistics for NC

Request for Endorsement From the Justus-Warren Heart Disease and Stroke Prevention Task Force

- Recognition and timely diagnosis of stroke in babies and children remains a largely neglected area in need of improvement.
- No standardized education and training programs exist on a national level, let alone a statewide basis.
- We will develop, implement and disseminate a standardized education and training program to improve the knowledge and skills critical to the diagnosis and management of pediatric stroke in the state of North Carolina.
- Resources for CME have been published and can be utilized for this proposal.
- Our list of active stakeholders include physicians, advocacy leaders and the VP of the American Stroke Association.

Successful implementation in North Carolina would serve as a model for pediatric stroke education and training nationally.

Resources

- Pediatric Stroke: Diagnosis and Management in the Emergency Department, CME Course from Pediatric Emergency Medicine Practice, EBMEDICINE.NET (2019)
- An Update on Pediatric Stroke Protocol, Pediatric Emergency Care Volume 34, Issue 11, p 816- 817, November 2018 doi: 10.1097/01.pec.0000549579.20065.fa
- Carolina Acute Stroke Training, Pediatric Stroke Online Module 9
- Organizing for Acute Arterial Ischemic Stroke in Children, Originally published 31 Oct 2019 <u>https://doi.org/10.1161/STROKEAHA.119.025497</u> Stroke. 2019;50:3662-3668
- Management of Stroke in Neonates and Children: A Scientific Statement from the American Heart Association/American Stroke Association, Originally published 28 Jan 2019 <u>https://doi.org/10.1161/STR.000000000000183</u>Stroke. 2019;50:e51-e96
- Laney's Story: The Problem of Delayed Diagnosis of Pediatric Stroke, Pediatrics March 2019, e20183458; DOI: <u>https://doi.org/10.1542/peds.2018-3458</u>
- Laney's father <u>Brian Fitzsimons' video</u> of his testimony at a Maryland Legislative hearing, 2018. The proposed HB668 was to educate all Maryland schools on pediatric stroke.

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