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
https://doi.org/10.1161/STR.0000000000000183Stroke. 2019;50:e51-e96
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

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## Some Risk Factors for Pediatric Stroke

<table>
<thead>
<tr>
<th>PERINATAL</th>
<th>CHILDHOOD</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Cardiac disorders</td>
<td>- Congenital heart disease</td>
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<tr>
<td>- Coagulation disorders</td>
<td>- Cardiac disorders (e.g. Myocarditis)</td>
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<tr>
<td>- Infections</td>
<td>- Cerebral vascular disorders (e.g. Moyamoya, Arterial Dissection)</td>
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<tr>
<td>- Trauma</td>
<td>- Infections (e.g. Varicella, Meningitis)</td>
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<td>- Maternal placenta disorders</td>
<td>- Head or neck trauma</td>
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<tr>
<td>- Maternal medications and toxins</td>
<td>- Sickle cell disease</td>
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<tr>
<td><strong>In most perinatal strokes, no risk factors are ever found</strong></td>
<td>- Autoimmune disorders</td>
</tr>
<tr>
<td><strong>Overall risk for another stroke is extremely low, &lt; 1%</strong></td>
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</tr>
</tbody>
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American Heart Association, “Youths and Cardiovascular Diseases, Statistical Fact Sheet 2015 Update”.
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.
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 one year of age
- Developmental delays

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

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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
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

Nazhai

- Age 16
- Dancer
- Active in her church
- In the high school business program
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 [Pediatric Emergency Assessment, Recognition and Stabilization](#) (PEARS) and [Pediatric Advanced Life Support](#) (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
- **Laney’s Story: The Problem of Delayed Diagnosis of Pediatric Stroke**, Pediatrics March 2019, e20183458; DOI: https://doi.org/10.1542/peds.2018-3458
- Laney’s father [Brian Fitzsimons’ video](#) 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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