Newborn Myelomeningocele v1.4

Inclusion Criteria
• Newborn Myelomeningocele neural tube defect requiring early back closure with or without placement of external ventricular drain (EVD)

Exclusion Criteria
• Prenatal closure
• Closure done at outside hospital
• Skin-covered neural tube defects

PHASE I (PRE-OP)

Pre-Op Consultations
• NICU Medical Control (on-call Neonatologist) to notify Neurosurgery and Neurodevelopmental when aware of transfer. Neurosurgery to call NICU if they hear first
• Neurosurgery will coordinate with Plastic Surgery
• Urology if prenatal hydronephrosis diagnosis (repeat ultrasound done)
• OT/PT
• Nutrition and TPN
• Social Work
• Patient Navigator if needed

Pre-Op Imaging and Monitoring
Neurologic
• Only low-dose fiducial STEALTH CT on admission, OFC daily, neuro checks every 4 hours, apnea and bradycardia monitoring
Cardiac
• Pre-op transthoracic echo (not indicated if normal prenatal echo done by pediatric cardiologist exists and no suggestion of cardiac disease on physical exam)
• Sole finding of functional/transitional murmur does not warrant pre-op echo

Pre-Op Feeding
• Baby may be fed only maternal expressed breast milk/colostrom (no going to breast) up to 10ml/per kilogram per day by PO preoperatively then follow normal preoperative NPO. DO NOT substitute with formula
• First 24 hours “starter TPN” D10 + amino acids PIV

Renal Imaging Recommendations

Positioning and Activity
• Position: Prone
• Side-lying also acceptable, no weight on myelomeningocele lesion unless required for resuscitation

Outside birth hospital transport and communication to SCH NICU
• Urine/Stool Output
• Fluids/Feeding
• Hepatitis B vaccine status
• Review of mother’s records including SCH Prenatal Counseling records under mother’s SCH ID# (fetal cardiology report, genetic testing/outside lab results)
• Imaging reports (prenatal, infant, maternal) hydronephrosis, ventricular size, echocardiogram
• Cord blood drawn for genetic testing (yes/no)
• Transport and Pre-Operative Stabilization of the Unrepaired Myelomeningocele (for SCH only)

Surgery
within 24-48 hrs

Go to Post Op

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Next Expected Review: September 2021
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**Incision Care, Positioning, Activity**
- Mepilex border lite dressing replaced as directed by Plastic Surgery
- Baby to be prone/side-lying for at least 2 weeks, per ongoing evaluation by Plastic Surgery provider
- Plastic Surgery provider will assess incision daily
- After Plastic Surgery provide determination that wound is healing appropriately baby may be positioned supine/on back
- Activity, including holding and breastfeeding, is ad lib with positioning limitations

**Post-Op Feeding**
- Breastmilk fed is preferred and should be encouraged
  - OT/PT should ideally be present for first oral feeding post-op
  - Multivitamin with iron unless fully formula fed
  - Initiate PO soon after surgery
  - Wean IV fluids as PO feeding progresses
  - Breastmilk and Formula Feeding: Click to see algorithm

**Tubes and Drains**
- Goal to remove indwelling urinary catheter within 24 hours post-op and begin Clean Intermittent Catheterization (CIC) protocol per GOC: Infant with Myelomeningocele, 10558 (for SCH only)
- Patients with EVD can be managed in NICU or on floor

**Bladder Management**
- Clean Intermittent Catheterization (CIC) protocol per GOC: Infant with Myelomeningocele, 10558 (for SCH only)

**Post-Op Imaging and Monitoring**
- OFC daily, M/Th cranial ultrasound, neuro checks every 2 hours times 6 hours then every 4 hours, apnea and bradycardia monitoring
- Unsedated neuroaxis MRI of spine to be performed later in admission to avoid extended anesthesia at time of initial closure
- ECHO prior to discharge to confirm no subtle cardiac findings unless done preoperatively

**Post-Op Consultations**
- Neurodevelopmental
- Neurosurgery
- Plastic Surgery
- Urology after renal ultrasound done
- Medically Complex Child (MCC)
- Nutrition
- Lactation
- OT/PT
- Social Work

**Babies are ok to transfer out of NICU to floor when these minimum criteria are met:**
- Able to manage temperature
- No apneic spells and bradycardia requiring interventions
- Post-op care remains the same on the floor

**Routine Sleep Study**
- Not recommended as a newborn

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Required family teaching to start once stable post-op
- Our Myelomeningocele Journey PE2954
- Spina Bifida PE056
- Spina Bifida Skin Care PE1130
- Hydrocephalus PE2482
- Signs of Respiratory Distress in your Child PE128
- Urinary Tract Infections PE179
- Clean Intermittent Catheterization PE118
- Voiding Log PE1641
- Living with Spina Bifida book
- Signs and symptoms of increased ICP
- Head Circumference measurement and tracking
- Wound Care/Bathing
- Nutrition/Feeding
- Exercise/positioning and handling
- Car seat teaching - Travel Safety PE1654 Car Bed PE2420
- Verify patient progression status on cathing protocol to be documented in physician discharge summary and nursing depart instructions

Discharge Coordination
- Car seat challenge passed
- PCP identified and appointment scheduled within 3-7 days of discharge
- Care Coordination to initiate supply orders with homecare (home monitors, feeding, cath supplies)
- Referral to Early Intervention Program
- SCH follow-up appointments scheduled
- Transitional Longitudinal Care (TLC) coordination with Care Coordination
- Care Notebook

Coordinated follow up 1-2 weeks after discharge
- Neurodevelopmental ARNP (discuss Orthopedics referral)
- Urology ARNP or RN if on cathing program
- Neurosurgery ARNP (unless shunted and wound check completed inpatient)
- Plastic Surgery if wound concerns
- OT/PT if indicated

Coordinated Spina Bifida Neurodevelopmental Clinic
2-3 months post discharge to be scheduled at discharge
- Neurodevelopmental
- NDV Social Work
- NDV Nutrition
- Neurosurgery (imaging to be scheduled at discharge)
- Urology (imaging to be scheduled at discharge)
- OT/PT if indicated

Discharge Criteria
- Teaching complete
- Supplies ordered
- Follow up appointments scheduled
- Medically cleared by Neurosurgery and Plastic Surgery

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Additional Urology testing
All testing including urodynamics and VCUG are to be ordered by Urologist after consultation

Mother’s prenatal records
- yes:
  - Prenatal Ultrasound done during 2nd or 3rd trimester indicates moderate or more bilateral hydronephrosis
- no:
  - Renal Ultrasound
    - Within 72 hours post-natal life, taking into consideration newborn's hydration status. Can be completed after back closure
    - Urology consulted after u/s completed and prior to discharge
    - First 24 hours of post-natal life obtain Renal/Bladder Ultrasound
    - Consult Urology
    - Neither the presence nor absence of renal ultrasound or consult should stop or delay surgery
Newborn Myelomeningocele: Standard Feeding
Infants BW > 2.5 kg

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Feeding Modality

Breastmilk

All Bottle or NG fed
• 1 Kcal/oz Beneprotein per all feeds
• 1 ml multivitamin with iron/day

100% Breastmilk

PO Feeding (goal to breast feed)
• 2k cal/oz Beneprotein per 4 feeds (50%)
• 1 ml multivitamin with iron/day

Infant Birth Weight < 2.5kg
• Infants < 1.8 kg will be fortified with human milk fortifier, Complete Amino Acids per unit protocol. (breastmilk fed)
• Infants 1.8-2.5 kg may benefit from supplementation above that described in above standard feeding guideline. (breastmilk fed)

Formula

Partial (formula)

• Protein Supplementation (Beneprotein) individualized with goal of 2.5 gm/kg/day
• May need multivitamin with iron (0.5-1 ml/day)
• Provide vitamin D 400 INT units/day

No protein supplement or multivitamin with iron supplement. Provide vitamin D 400 INT units/day

Adjustments per intake feeding and growth

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**Newborn Myelomeningocele Approval & Citation**

Approved by the CSW Newborn Myelomeningocele Pathway for 9/29/16 go live date.

**CSW Newborn Myelomeningocele Team:**

<table>
<thead>
<tr>
<th>Category</th>
<th>Name</th>
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<tbody>
<tr>
<td>Neurodevelopmental, Owner</td>
<td>William Walker, MD</td>
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<td>Neonatology, Stakeholder</td>
<td>Elizabeth Jacobson, MD</td>
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<td>Urology, Stakeholder</td>
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<td>Neurosurgery, Stakeholder</td>
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<td>MCC, Stakeholder</td>
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<td>Plastic Surgery, Stakeholder</td>
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<td>OT/PT, Stakeholder</td>
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<td>Clinical Pharmacy</td>
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**Clinical Effectiveness Team:**

<table>
<thead>
<tr>
<th>Role</th>
<th>Name</th>
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<tbody>
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<td>Heather Marshall</td>
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<tr>
<td>Librarian</td>
<td>Jackie Morton, MLS</td>
</tr>
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**Executive Approval:**

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<tr>
<th>Role</th>
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<tr>
<td>Sr. VP, Chief Medical Officer</td>
<td>Mark Del Beccaro, MD</td>
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<tr>
<td>Sr. VP, Chief Nursing Officer</td>
<td>Madlyn Murrey, RN, MN</td>
</tr>
<tr>
<td>Surgeon-in-Chief</td>
<td>Bob Sawin, MD</td>
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Head CT is the preferred postnatal imaging modality rather than Cranial ultrasound or MRI prior to the initial surgery in infants with meningomyelocele because the primary purpose of initial postnatal imaging is to define the degree of ventriculomegaly and other structural abnormalities. Obtaining a fiducial CT of the brain is the imaging method of choice to meet this goal. This methodology allows better direct observation of the infant during the procedure, can be set up to minimize radiation exposure to the infant, and provides a correlation between radiologic and anatomic landmarks that can be utilized to improve the accuracy of future ventricular shunt placement, if required.

Key assumptions include:
1. Defining a specific imaging modality eliminates the ordering of duplicative studies and variance among medical and surgical providers in a patient population that, while not rare, is not a frequent admission to the ICU.
2. The use of fiducial CT images improves the accuracy of and outcomes from subsequent ventricular shunt placement. (Required in about 85% of infants born with meningomyelocele in this institution.

This recommendation is based on expert opinion.

A (cost-benefit, waste reduction, cost-minimization, cost-effectiveness) was applied. Estimated yearly cost savings is $3405.

The average direct cost per account of Head CT 2015 was $76 which is the preferred study. The average direct cost per account for 2015 cranial ultrasound is $80 and MRI brain limited is $147. Assumptions included a yearly volume of 15 patients with all patients needing Head CT prior to surgery and no patients needing MRI brain limited and cranial ultrasound prior to surgery.
<table>
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<th>FINAL CSW VALUE STATEMENT</th>
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| Routinely obtaining coagulation studies prior to surgery in infants born with meningo(myelo)cele is not recommended. All of these infants would have already been treated with intramuscular Vitamin K which would address the issues of greatest concern in all infants. The interpretation of any information obtained from these studies is complicated by variable reference values and would not alter the proposed treatment regimen or timing. While the required blood volume to do this test, in and of itself, is not significant, there is a strong desire by ICU personnel to limit the amount and frequency of laboratory studies requiring blood in all infants. By preferred because (review benefits/harms and estimated cost difference). Key assumptions include:
| 1. Maternal factors that would predispose the infant to abnormal bleeding (maternal thrombocytopenia, HELLP syndrome in the mother, family history of bleeding disorders) will be identified prior to surgery.
| 2. Neither Neurosurgery nor Plastic Surgery feel that the initial neural tube defect closure will result in significant blood loss.
| This recommendation is based on (expert opinion). A (cost-benefit, waste reduction, cost-minimization, cost-effectiveness) was applied. Estimated yearly cost savings is $195. |

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<tr>
<th>COST SAVINGS HYPOTHESIS NARRATIVE</th>
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<td>The average direct cost per account of prothrombin time (PT) measure in 2016 was $13. Assumptions included a yearly volume of 15 patients with all patients not obtaining this study. Estimated yearly cost savings is $195.</td>
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</tbody>
</table>
Routinely obtaining a surface wound culture at the neural tube defect site is not recommended whether the neural placode covering is intact or ruptured. This type of culture would only identify surface pathogens and would better describe the in utero or vaginal microbiom rather than the clinical state of or the risk of infection to the infant. Test results would not change the course of treatment for the child and would not be available until after the initial closure procedure. These children are routinely started on parenteral antibiotics prior to their initial surgery (Ampicillin, Gentamicin). Other protocols for intensive care unit monitoring of MRSA (methicillin resistant staphyllococcus aureus) are already in place with prescribed culture sites. The recommendation is based on expert opinion. A (cost-benefit, waste reduction, cost-minimization, cost-effectiveness) was applied. Estimated yearly cost savings is $570.

The average direct cost per account of wound culture (Other Source) in 2016 was $38. Assumptions included a yearly volume of 15 patients with all patients not obtaining this study. Estimated yearly cost savings is $570.
There is insufficient evidence available to recommend that a formal assessment of sleep disordered breathing (polysomnography) be done during the newborn period based solely on the diagnosis of meningomyelocele and/or Chiari malformation alone. There is no consensus regarding the initiation or timing of these assessments. There is no current validated questionnaire to identify a high risk group of MM infants with SDB. This recommendation is based on expert opinion.

A (cost-benefit, waste reduction, cost-minimization, cost-effectiveness) was applied. Estimated yearly cost savings is $3780.

The average direct cost per account of polysomnography measure in 2016 was $252. Assumptions included a yearly volume of 15 patients with all patients not obtaining this study. Estimated yearly cost-savings is $3780.
This pathway was developed through local consensus based on published evidence and expert opinion as part of Clinical Standard Work at Seattle Children’s. Pathway teams include representatives from Medical, Subspecialty, and/or Surgical Services, Nursing, Pharmacy, Clinical Effectiveness, and other services as appropriate.

When possible, we used the GRADE method of rating evidence quality. Evidence is first assessed as to whether it is from randomized trial or cohort studies. The rating is then adjusted in the following manner (from: Guyatt G et al. J Clin Epidemiol. 2011;4:383-94.):

- **Quality ratings are downgraded if studies:**
  - Have serious limitations
  - Have inconsistent results
  - If evidence does not directly address clinical questions
  - If estimates are imprecise OR
  - If it is felt that there is substantial publication bias

- **Quality ratings are upgraded if it is felt that:**
  - The effect size is large
  - If studies are designed in a way that confounding would likely underreport the magnitude of the effect OR
  - If a dose-response gradient is evident

**Guideline – Recommendation is from a published guideline that used methodology deemed acceptable by the team.**

**Expert Opinion – Our expert opinion is based on available evidence that does not meet GRADE criteria (for example, case-control studies).**

**Quality of Evidence:**
- 🌟🌟🌟🌟 High quality
- 🌟🌟🌟 Moderate quality
- 🌟🌟 Low quality
- 🌟🌟🌟 Very low quality

Guideline
Expert Opinion
Summary of Version Changes

- **Version 1.0 (9/29/2016):** Go live.
- **Version 1.3 (9/27/2019):** Updated broken link to transport protocol.
Medical Disclaimer

Medicine is an ever-changing science. As new research and clinical experience broaden our knowledge, changes in treatment and drug therapy are required.

The authors have checked with sources believed to be reliable in their efforts to provide information that is complete and generally in accord with the standards accepted at the time of publication.

However, in view of the possibility of human error or changes in medical sciences, neither the authors nor Seattle Children’s Healthcare System nor any other party who has been involved in the preparation or publication of this work warrants that the information contained herein is in every respect accurate or complete, and they are not responsible for any errors or omissions or for the results obtained from the use of such information.

Readers should confirm the information contained herein with other sources and are encouraged to consult with their health care provider before making any health care decision.
Literature Search Strategy

Search Methods, Newborn Myelomeningocele, Clinical Standard Work

Studies were identified by searching electronic databases using search strategies developed and executed by a medical librarian, Jackie Morton. The searches for myelomeningocele were performed in March 2016. The following databases were searched – on the Ovid platform: Medline and the Cochrane Database of Systematic Reviews; elsewhere – Embase, National Guideline Clearinghouse, TRIP and Cincinnati Children’s Evidence-Based Care Guidelines. Clinical questions regarding myelomeningocele were searched from 2006 to date. A search with no evidence categories, study, or publication type limitations was conducted for infants, ages 0 – 24 months. A second search limited to certain evidence categories, such as relevant publication types, Clinical Queries filters for diagnosis and therapy, index terms for study types and other similar limits was conducted for "pediatric" concepts in the title, abstract, or keywords fields. All retrieval was limited to English language. In Medline and Embase, appropriate Medical Subject Headings (MeSH) and Emtree headings were used respectively, along with text words, and the search strategy was adapted for other databases using their controlled vocabularies, where available, along with text words. Concepts searched were spinal dysraphism, spina bifida, meninogomyelocele or myelomeningocele or neural tube defects.

Jackie Morton, MLS - August 8, 2016

Identification

612 records identified through database searching

0 additional records identified through other sources

Screening

612 records after duplicates removed

612 records screened

528 records excluded

Eligibility

84 records assessed for eligibility

65 full-text articles excluded, 62 did not answer clinical question, 3 did not meet quality threshold, 0 outdated relative to other included study

Included

19 studies included in pathway

Flow diagram adapted from Moher D et al. BMJ 2009;339:bmj.b2535
Included Studies


Additional References