A DIFFERENT LOOK AT NTD PREVENTION

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OPENING REMARKS FROM LINDSEY

• Type I or closed lip
• Type II or open lip
• Unilateral or bilateral
• Developmental delay
• Seizures
• Intellectual disability
• Hydrocephalus
• Partial or complete paralysis
• Poor muscle tone

SCHIZENCEPHALY

• Schizencephaly (“split brain”) is a rare congenital brain malformation in which abnormal slits or clefts form in the cerebral hemispheres of the brain.
• Type I or closed lip
• Type II or open lip
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SKYLAR'S MRI NORMAL BRAIN MRI

SKYLAR'S CURRENT HEALTH ISSUES

- Schizencephaly (CMS/HCC)
- CP (cerebral palsy), spastic, quadriplegic (CMS/HCC)
- Obstructive hydrocephalus (CMS/HCC)
- Cortical visual impairment
- Chronic subdural hematoma (CMS/HCC)
- Moderate persistent asthma without complication
- Chronic non-seasonal allergic rhinitis
- Obstructive sleep apnea syndrome
- Airway clearance impairment
- Chronic lung disease
- Brucyelida
- Secondary hypertension
- Dysphagia, unspecified type
- Gastroesophageal reflux disease, esophagitis presence not specified
- Urinary retention
- S/P placement of VNS (vagus nerve stimulation) device
- Nontraumatic subdural hygroma
- Hypothermia, subsequent encounter
- Developmental delay
**LIFE OF A CHILD WITH AN NTD**

- 441 Hospital stays = 150 days total
- 304 Speciality clinic visits
- 43 ER Visits
- 14 Brain surgeries
- 30 Overall surgeries

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**THE TRUTH ABOUT RECURRENCE PREVENTION**

- After Skylar’s birth, routine care
- Annual visits, no mention of folic acid
- Considerations of a future pregnancy – what are my options?
- Asked a friend from special needs community for advice based on her experience
- Higher dose of folic acid
- Genetic counselor, high risk OB
WHAT SHOULD RECURRENCE PREVENTION BE LIKE?

MINNESOTA RECURRENCE PREVENTION PROJECT GOALS

1. Understand providers’ role: current NTD-diagnosed pregnancy, future pregnancies
2. Get advice from women who had a prior NTD-affected pregnancy
3. Learn from state surveillance programs that do recurrence prevention

TALKING TO PROVIDERS ABOUT RECURRENCE PREVENTION
MN PROVIDERS FIND RECURRENCE PREVENTION CHALLENGING

- Unplanned pregnancies
- Lack of continuity in care
- Referred to specialists
- Insurance dropped, changes, etc.
- No preconception care, late prenatal care
- Sometimes cultural barriers to supplements

PROVIDER RECOMMENDATIONS

For health care providers:
- Multidisciplinary teams,
- Referrals within their health system
- Build prompts in EHRs into the mother's problem list
- Consistent messaging for routine and high risk care appointments

Role for MDH:
- Education for different providers to ensure consistent message
- Statewide campaign to raise awareness of preconceptional folic acid generally and for recurrence
- Need for “a database for previous NTD-affected pregnancies” to target mass mailings (i.e. BD surveillance)

TALKING TO PARENTS ABOUT RECURRENCE PREVENTION
WHAT PARENTS SHARED

- Trauma and insensitivity
- Needs:
  - Not to feel alone
  - It’s not your fault
  - Clear messages about how much folic acid is needed in the future
  - Present the range of possible outcomes, not just worst-case
- If lost a child,
  - It’s OK… not to be OK, to move on, to ask for help
- Resource list

WHEN TO TALK ABOUT RECURRENCE PREVENTION

- In packet for parents to take home
- After delivery, when providing resources
- As part of regular, long term follow up
- Home visits
- Well child visits
- At mother’s annual visits
- No agreement on ‘ideal’ time
- Clear support for the importance of folic acid campaigns for all women of reproductive age
- Most didn’t know prior to their pregnancy

WHO DO THEY WANT TO HEAR THESE MESSAGES FROM

- Provider
- State or local health department – esp. for parents who lost their child
- Other health professionals: Genetic counselor, Doula
- Peers"
IMPORTANT THINGS TO MENTION

- Consistent message: dosage and timing
- Describe risk for future pregnancy
- 3% risk of recurrence
- Don’t imply that folic acid is 100% effective
- Genetic counseling
- Include fathers

RECOMMENDATIONS FOR WOMEN WITH A PRIOR NTD-AFFECTED PREGNANCY

Not planning a pregnancy:
- 400 mcg of folic acid daily

Planning a pregnancy:
- 4,000 mcg of folic acid daily
- Start 1 month before trying to become pregnant
- Continue through the first 3 months of pregnancy

Source: Recommendations: Women and Folic Acid, CDC
<table>
<thead>
<tr>
<th>WHAT</th>
<th>WHO</th>
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<tbody>
<tr>
<td>• Letter with brochure</td>
<td>• Program staff</td>
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<tr>
<td>• Mail packet</td>
<td>• Community partnerships or contracts</td>
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<tr>
<td>• Contact by phone</td>
<td>• Newborn Screening</td>
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<tr>
<td>• Contact in person</td>
<td>• LPH</td>
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<tr>
<td>• Distribute vitamins through LPH, family planning</td>
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<td>• Outreach at health fairs</td>
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<td>• Trainings to home visiting nurses</td>
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**STATE RECURRENCE PREVENTION ACTIVITIES, CONTINUED**

**EVALUATION**

• Process measures:
  - Letters sent
  - Vitamins distributed
  - Social media analytics
  - Satisfaction postcard with NTD letter
  - Outcome measures: challenging

**RECOMMENDATIONS**

• Start small
• Ask experts
• Form partnerships
• Engage families directly

**ADVICE TO BIRTH DEFECTS PROGRAMS ABOUT NTD PREVENTION**

• For recurrence prevention,
  - It’s needed – you can do it!
  - No perfect way or time
  - Use gentle and caring language
  - Use existing resources (CDC)
  - Explore partnerships
  - Folic acid recommendations need to be consistent and repeated
  - Importance of campaigns to promote folic acid recommendations for ALL women of child bearing age
CLOSING REMARKS FROM LINDSEY

QUESTIONS!

THANK YOU!

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