

A DIFFERENT LOOK AT NTD PREVENTION

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OPENING REMARKS FROM LINDSEY



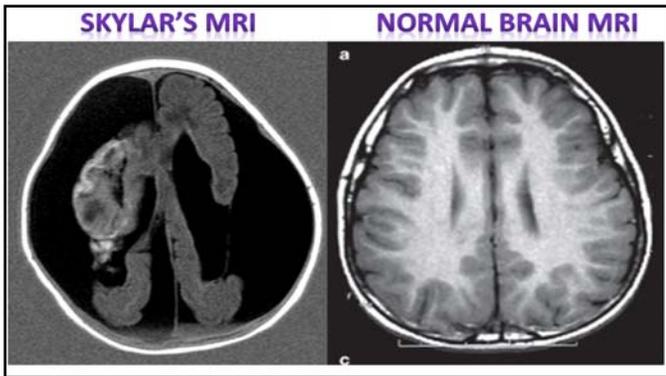
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SCHIZENCEPHALY

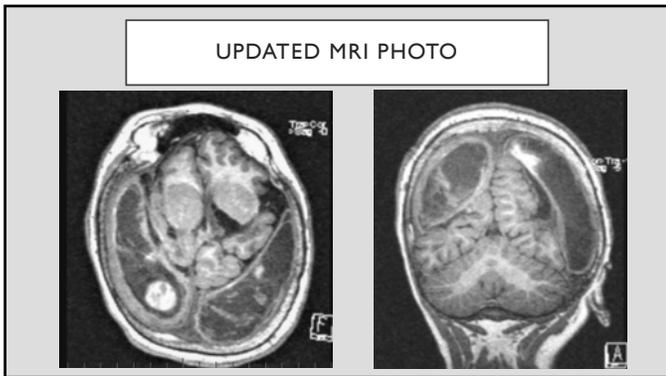
• Schizencephaly (“split brain”) is a rare congenital brain malformation in which abnormal slits or clefts form in the cerebral hemispheres of the brain.

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

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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
- Bradycardia
- 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

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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

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WHAT SHOULD RECURRENCE PREVENTION BE LIKE?

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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

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TALKING TO PROVIDERS ABOUT RECURRENCE PREVENTION

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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

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PROVIDER RECOMMENDATIONS

- | | |
|---|---|
| <ul style="list-style-type: none">• For health care providers:<ul style="list-style-type: none">• 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 | <ul style="list-style-type: none">• Role for MDH:<ul style="list-style-type: none">• 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) |
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TALKING TO PARENTS ABOUT RECURRENCE PREVENTION

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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,
 - that their baby matters
 - It's OK... not to be OK, to move on, to ask for help
 - Resource list

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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

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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*

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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

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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](#)

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TALKING TO STATES ABOUT RECURRENCE PREVENTION

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STATE RECURRENCE PREVENTION
ACTIVITIES

WHAT

- Letter with brochure
- Mail packet
- Contact by phone
- Contact in person
- Distribute vitamins through LPH, family planning
- Outreach at health fairs
- Trainings to home visiting nurses

WHO

- Program staff
- Community partnerships or contracts
- Newborn Screening
- LPH

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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

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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

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THANK YOU!

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