Womb to tomb: lifespan care for spina bifida

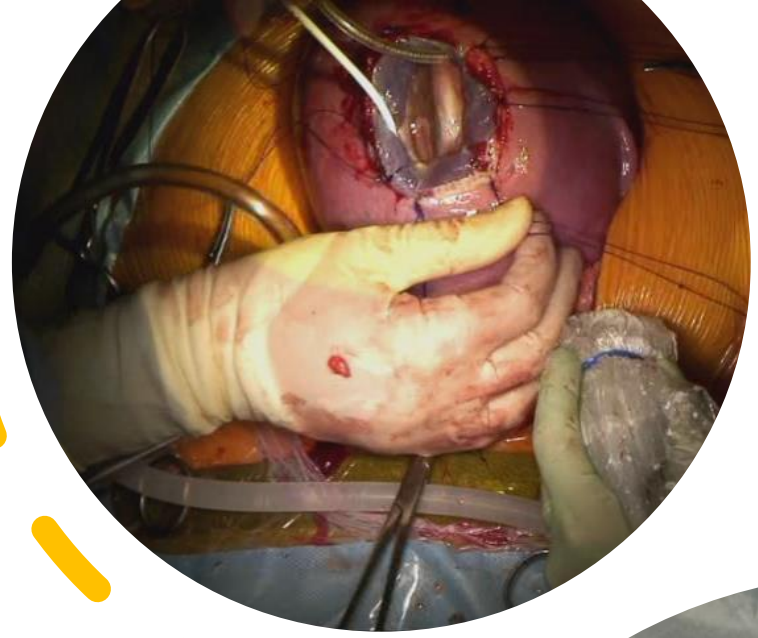
Andrew B. Foy, MD, FAANS
Associate Professor of Neurosurgery
Medical Director, Comprehensive Spina Bifida Clinic

Children's Wisconsin

Medical College of Wisconsin

Outline

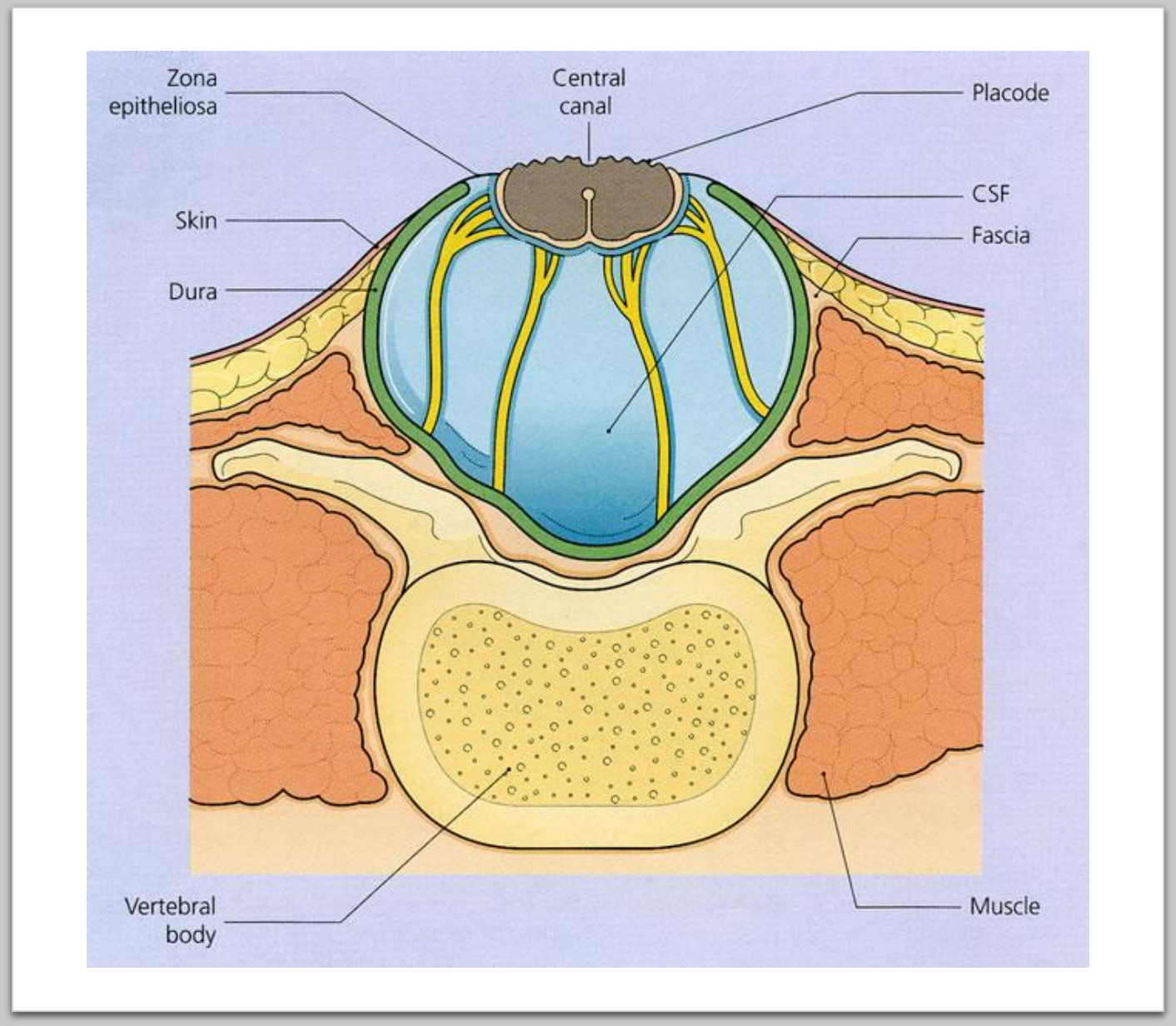
- I have no disclosures
- Goals
  - Overview and epidemiology
  - Fetal and neonatal management
  - Childhood and adult care



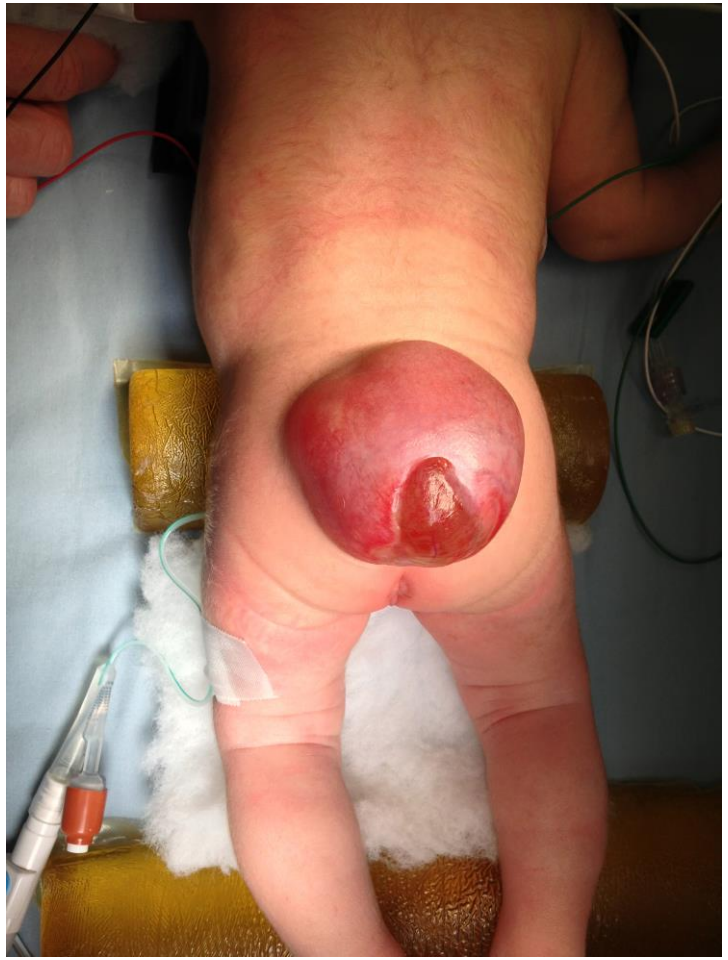
Open Spina Bifida

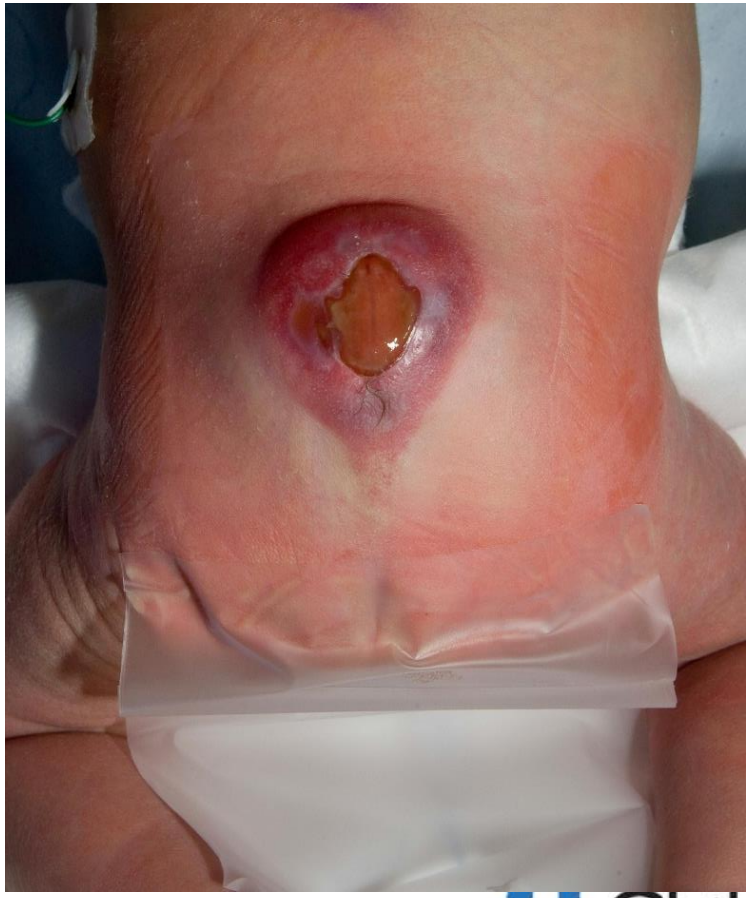
- Failure of dysjunction of the neural tube from the ectoderm early in fetal life leads to open defect with exposed neural elements (neural placode)

- Failure of primary neurulation



Open spina bifida



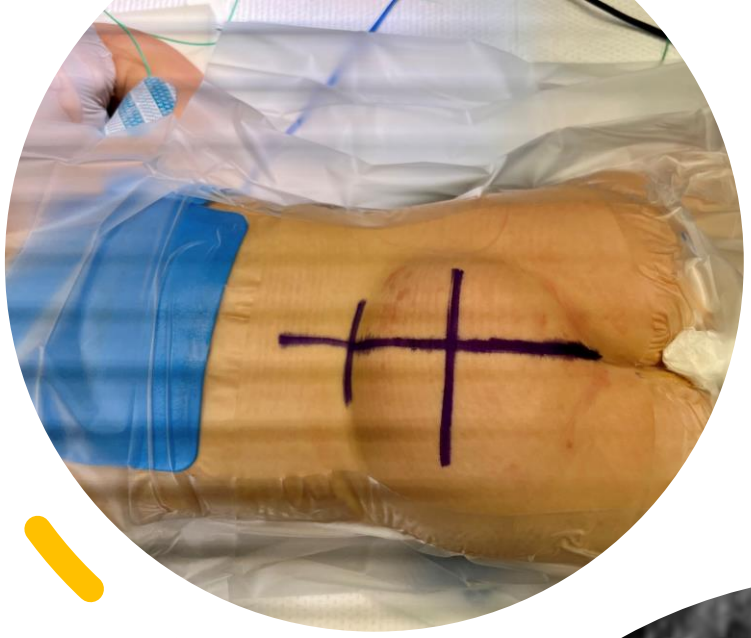


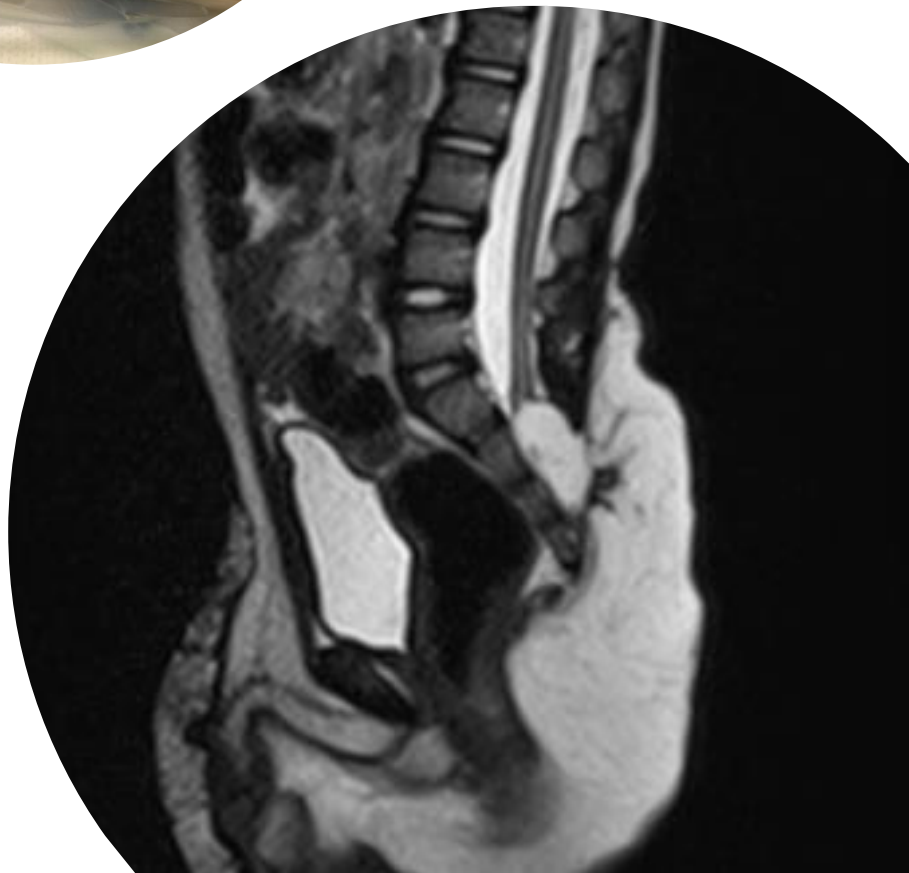
Children's Wisconsin

MEDICAL COLLEGE OF WISCONSIN

Closed spina bifida

- 10-15% of patients in spina bifida clinic
- 1170 out of ~10,000 patients in the National Spina Bifida Patient Registry (NSBPR)
- Similar management, less risk of hydrocephalus





Epidemiology

3.86 per 10,000 live births in USA	• 20-25 new cases in WI per year based on 2020 data
Risk factors	• Affected sibling (1-2% risk if prior child has myelomeningocele) • Decreased maternal folate intake • Teratogens (valproate and carbamazepine)
Possible environmental factors	• Geographic location • Maternal diabetes, maternal age, maternal alcohol abuse

Children's Wisconsin

Medical College of Wisconsin

Mai CT, Isenburg JL, Canfield MA, et al. National population-based estimates for major birth defects, 2010-2014. *Birth Defects Res.* 2019;111(18):1420-1435.

Epidemiology

Prevalence: 3.92/10,000 live births

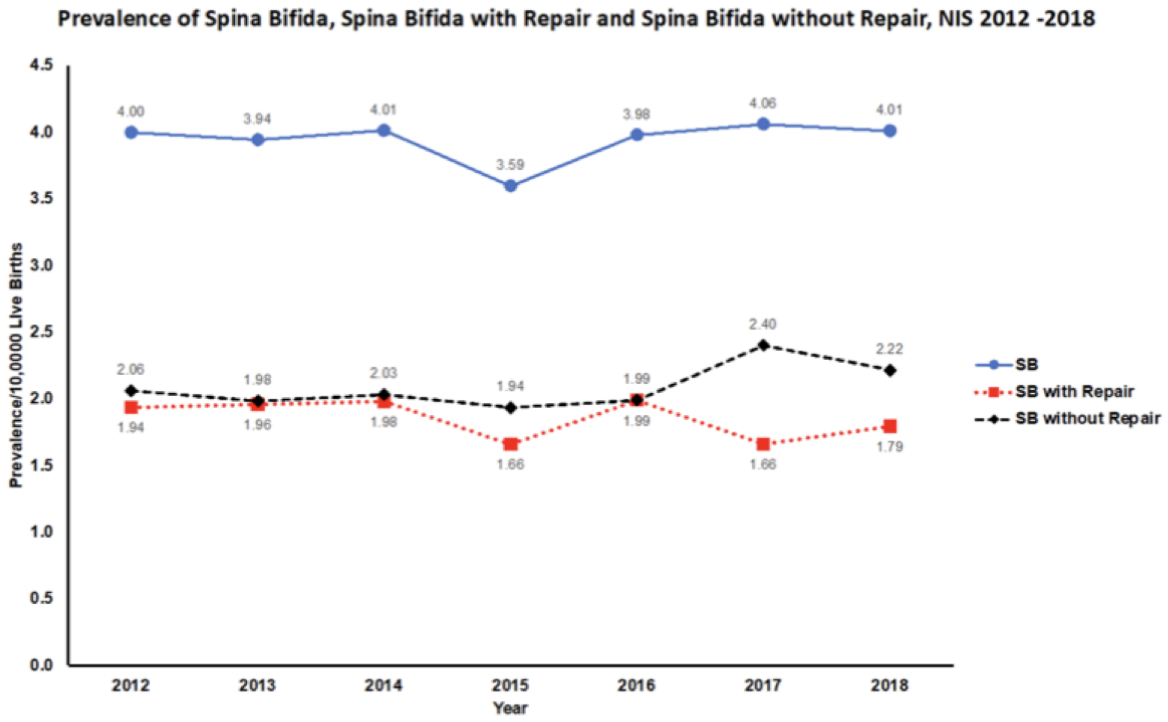


Fig. 2 Overall prevalence of spina bifida, prevalence of spina bifida with repair, and spina bifida without repair per 10,000 live births in the HCUP-NIS, 2012–2018

Child's Nervous System
https://doi.org/10.1007/s00381-022-05704-3

ORIGINAL ARTICLE

Trends in the early care of infants with myelomeningocele in the United States 2012–2018

Benjamin J. Best[1,2] · Erwin T. Cabacungan[3,4] · Susan S. Cohen[3,4] · Irene Kim[1,2] · Eileen C. Sherburne[2,5] · Kathleen J. Sawin[5,6] · Audrey Roach[2] · Andrew B. Foy[1,2]

Received: 18 August 2022 / Accepted: 13 October 2022

Global problem

- 300,000 new cases of neural tube defect/anencephaly globally per year
  - 75% result in abortion, stillbirth or death before age 5.
- Much of this is due to absence of maternal folate
- Global Alliance for the Prevention of Spina Bifida–Folate
- Over 300 countries with no government mandated folate fortification.
  - Mostly low/middle income

Preventing birth defects, saving lives, and promoting health equity: an urgent call to action for universal mandatory food fortification with folic acid

Vijaya Kancherla, Lorenzo D Botto, Laura A Rowe, Nathan A Shlobin, Adrian Caceres, Anastasia Arynchyna-Smith, Kathrin Zimmerman, Jeffrey Blount, Zewdie Kibruyisfaw, Kemel A Ghotme, Santosh Karmarkar, Graham Fieggen, Sylvia Roozen, Godfrey P Oakley Jr, Gail Rosseau, Robert J Berry

	Number of people reached (millions)	Expected number of cases of anaemia averted in women of reproductive age	Expected number of NTDs averted	Expected number of deaths under the age of 5 years averted	Expected number of DALYs averted	Expected economic value of DALYs averted (million US$)
India*	553	24 950 107	22 006	20 410	2 198 103	5532
China	1285	28 831 810	14 037	11 681	1 701 396	20 298
Bangladesh	145	3 194 605	4154	3857	369 392	594
Nigeria	109	5 374 530	3731	3519	362 564	2364
Egypt	89	1 896 955	2077	1783	161 352	699
Ethiopia	85	1 695 531	1397	1315	140 088	141
Philippines	81	809 657	1089	954	102 517	537
Angola	9	365 698	816	769	57 522	383
Morocco	32	1 016 226	547	454	66 193	310
Ghana	20	722 468	531	499	54 008	147
Benin	10	503 202	375	354	38 998	64
Indonesia	25	540 840	312	274	35 071	196

Estimates are for mandatory fortification of wheat flour or rice, or both, in selected low-income and middle-income countries in 2019 with a high potential for food fortification.[15] Data are sorted by expected number of NTDs averted. DALYs=disability-adjusted life years. NTDs=neural tube defects (largely comprising spina bifida and anencephaly). *Includes 17 Indian states: Andhra Pradesh, Assam, Bihar, Chhattisgarh, Haryana, Himachal Pradesh, Jharkhand, Karnataka, Kerala, Madhya Pradesh, Maharashtra, Orissa, Punjab, Rajasthan, Tamil Nadu, Uttar Pradesh, and West Bengal.

Table: **Estimated annual health and economic benefits of implementing mandatory food fortification with folic acid**

Consequences of the disease

- Chronic disease that requires lifelong medical care
  - High rate of neurogenic bowel and bladder
  - High rate of hydrocephalus
  - Variable motor and somatosensory deficits dependent on level of lesion
  - Scoliosis
  - Tethered cord syndrome
  - Orthopedic deformities
  - Can have clinically significant brainstem dysfunction/Chiari II
  - Skin breakdown

Children's Wisconsin

Medical College of Wisconsin

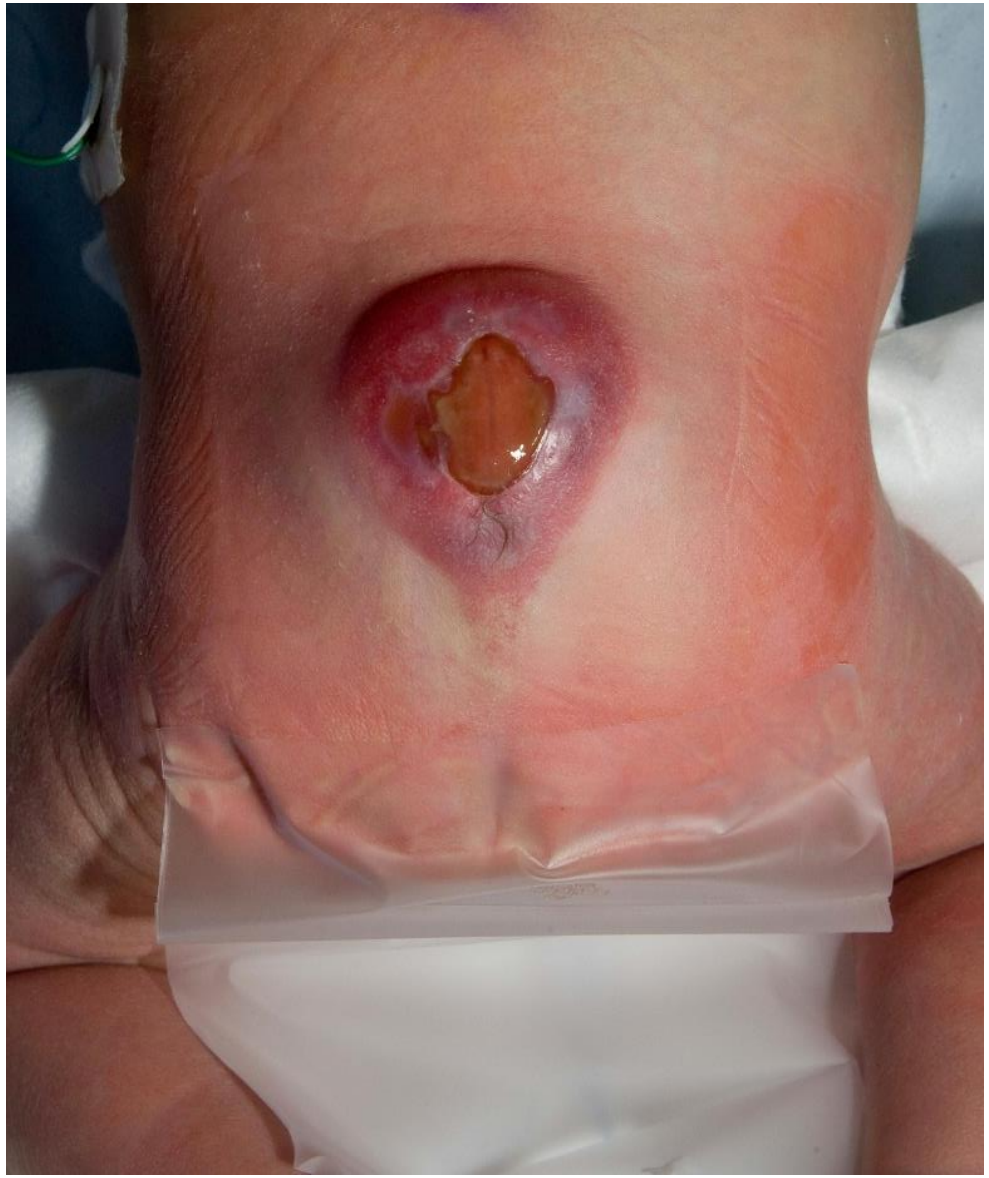
Two hit hypothesis

Neurologic injury to exposed neural tissue occurs due to:

1. Developmental defect itself

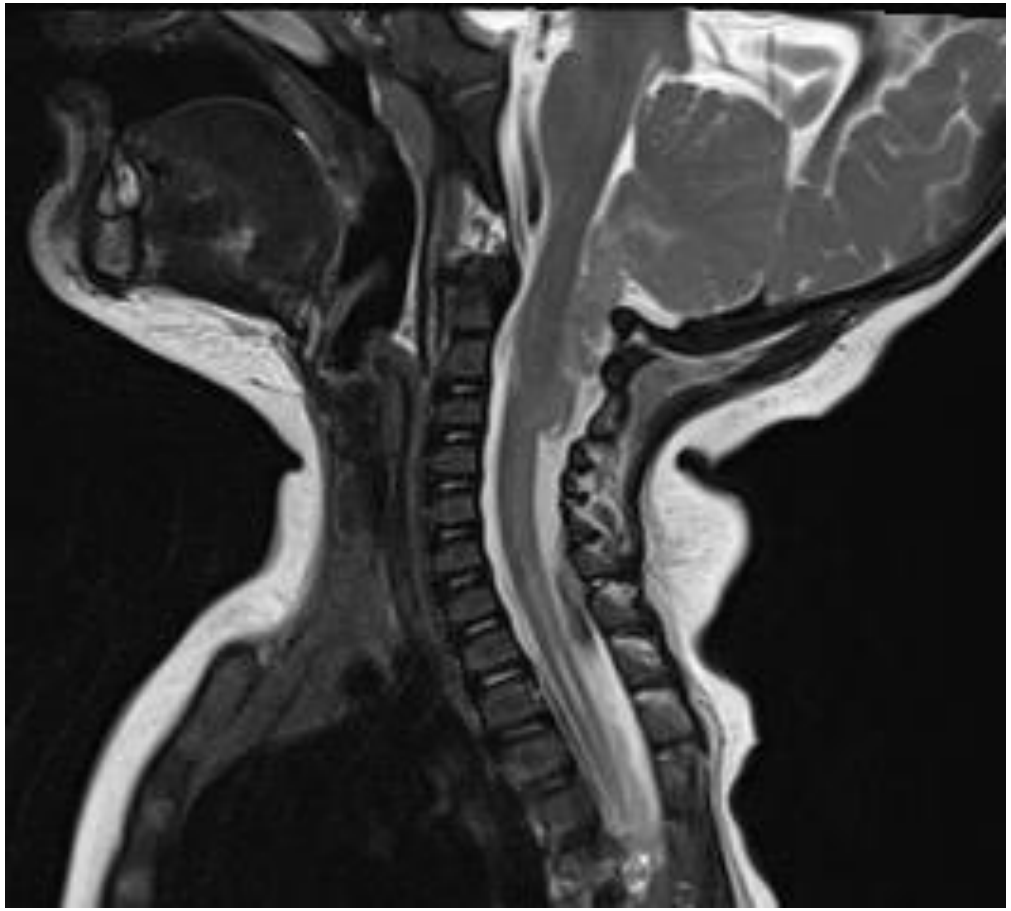
2. Exposure of neural elements to amniotic fluid

But it’s more complicated than that….



Chiari II

- Posterior fossa
  - Hindbrain herniation
  - Low lying torcular heterophili
  - Kinking of brainstem, pontine flexure
  - Beaking of the midbrain tectum
- Supratentorial
  - Enlarged massa intermedia
  - Interdigitation of the cortical sulci
  - Hypoplastic falx cerebri
  - Colpocephaly



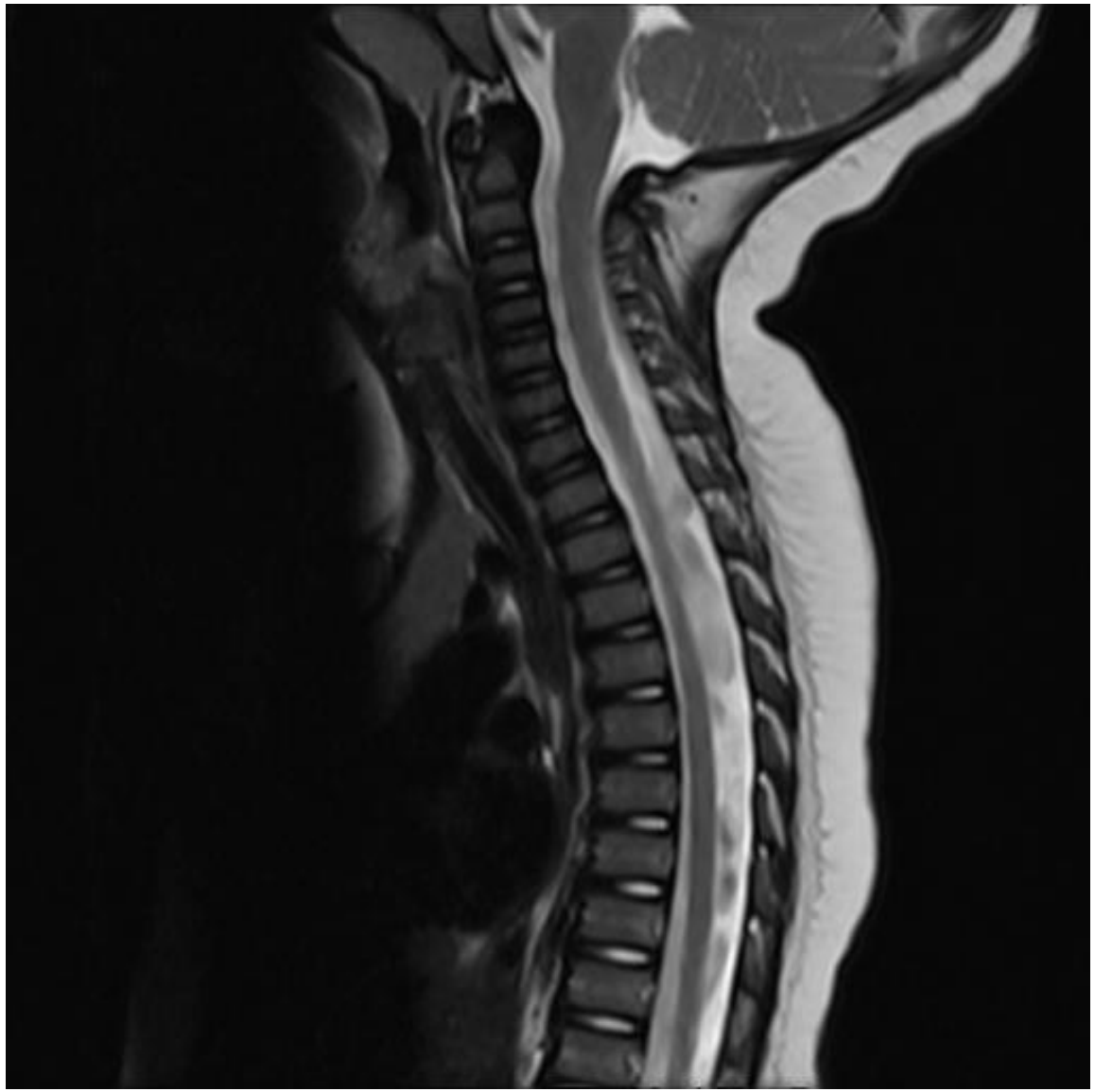
Children's Wisconsin

Medical College of Wisconsin

Rationale for fetal repair

- Prevention of “second hit” damage to neural placode from amniotic fluid

- Prevention of secondary cranial changes (amelioration of hindbrain herniation)



MOMS

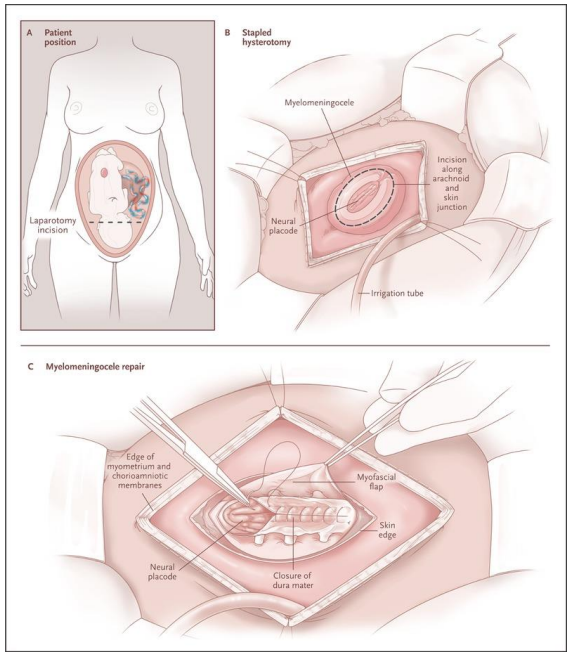
- NIH funded, randomized, prospective trial of open fetal repair versus standard post-natal closure
- Enrollment from 2003-2010 at three centers
- 183 fetuses were randomized
- Study was halted on interim analysis in 2010
- One of very few procedures with level I evidence

The NEW ENGLAND JOURNAL of MEDICINE

ESTABLISHED IN 1812 MARCH 17, 2011 VOL. 364 NO. 11

A Randomized Trial of Prenatal versus Postnatal Repair of Myelomeningocele

N. Scott Adzick, M.D., Elizabeth A. Thom, Ph.D., Catherine Y. Spong, M.D., John W. Brock III, M.D., Pamela K. Burrows, M.S., Mark P. Johnson, M.D., Lori J. Howell, R.N., M.S., Jody A. Farrell, R.N., M.S.N., Mary E. Dabrowiak, R.N., M.S.N., Leslie N. Sutton, M.D., Nalin Gupta, M.D., Ph.D., Noel B. Tulipan, M.D., Mary E. D'Alton, M.D., and Diana L. Farmer, M.D., for the MOMS Investigators*



Children's Wisconsin

MEDICAL COLLEGE OF WISCONSIN

Outcomes

- Primary end-points
  - Fetal death
  - Spinal fluid shunt
  - Motor function

Secondary end-points

- Reversal of hindbrain herniation
- Maternal and fetal morbidity

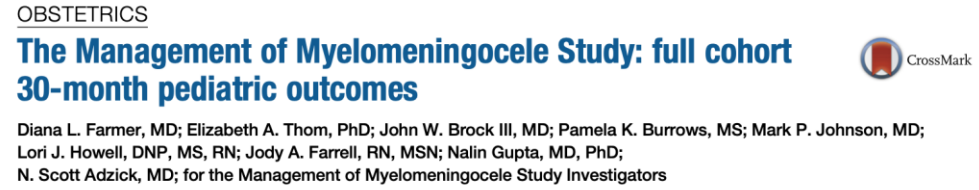
	Prenatal repair	Postnatal repair	p value
Shunt placed	40%	82%	<0.001
Hindbrain herniation	64%	96%	<0.001
Difference between function and anatomical level ≥2	32%	12%	0.02
Walk independently	42%	21%	0.01

Children's Wisconsin

Medical College of Wisconsin

MOMS long term

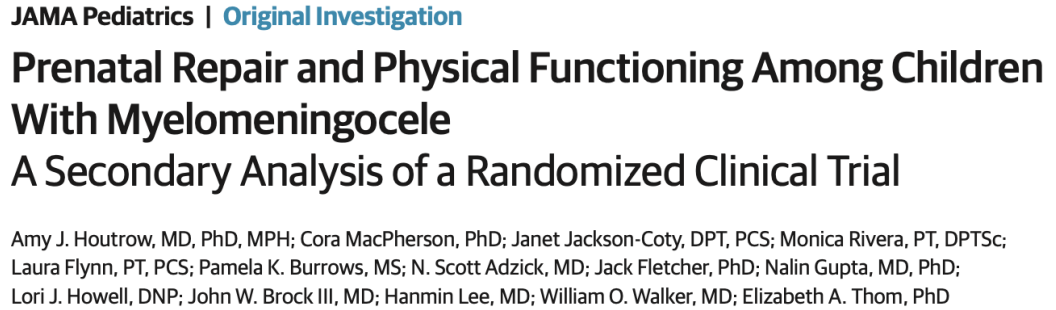
- Largely positive outcomes for the fetal repair cohort
  - More independent
  - Sustained improvement in physical functioning
  - Fewer surgeries
  - Similar cognitive outcomes
  - Similar urologic outcomes
  - Less brainstem dysfunction



OBSTETRICS

The Management of Myelomeningocele Study: full cohort 30-month pediatric outcomes

Diana L. Farmer, MD; Elizabeth A. Thom, PhD; John W. Brock III, MD; Pamela K. Burrows, MS; Mark P. Johnson, MD; Lori J. Howell, DNP, MS, RN; Jody A. Farrell, RN, MSN; Nalin Gupta, MD, PhD; N. Scott Adzick, MD; for the Management of Myelomeningocele Study Investigators

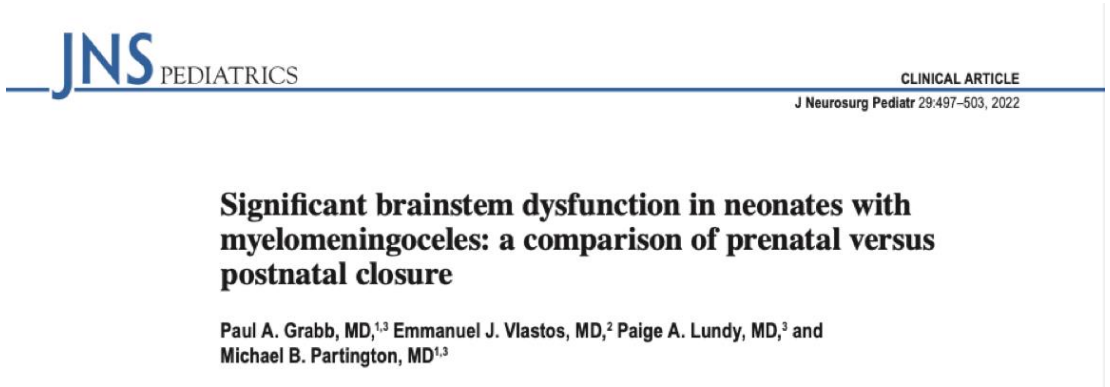


JAMA Pediatrics | Original Investigation

Prenatal Repair and Physical Functioning Among Children With Myelomeningocele

A Secondary Analysis of a Randomized Clinical Trial

Amy J. Houtrow, MD, PhD, MPH; Cora MacPherson, PhD; Janet Jackson-Coty, DPT, PCS; Monica Rivera, PT, DPTSc; Laura Flynn, PT, PCS; Pamela K. Burrows, MS; N. Scott Adzick, MD; Jack Fletcher, PhD; Nalin Gupta, MD, PhD; Lori J. Howell, DNP; John W. Brock III, MD; Hanmin Lee, MD; William O. Walker, MD; Elizabeth A. Thom, PhD



JNS PEDIATRICS

CLINICAL ARTICLE

J Neurosurg Pediatr 29:497–503, 2022

Significant brainstem dysfunction in neonates with myelomeningoceles: a comparison of prenatal versus postnatal closure

Paul A. Grabb, MD,[1,3] Emmanuel J. Vlastos, MD,[2] Paige A. Lundy, MD,[3] and Michael B. Partington, MD[1,3]

Children's Wisconsin

MEDICAL COLLEGE OF WISCONSIN

Some concerns

- ? Higher risk of dermal inclusion cyst
- Higher risk of tethered cord syndrome
- ETV/CPC for hydrocephalus enters the game

Pediatric Neurosurgery

Novel Insights from Clinical Practice

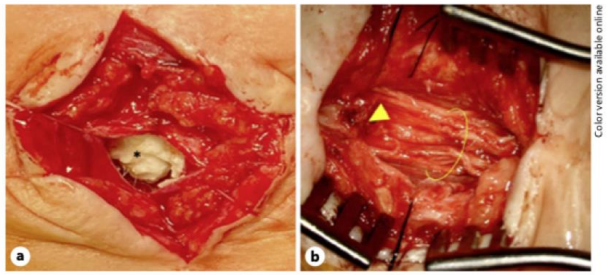
Pediatr Neurosurg 2022;57:371–375
DOI: 10.1159/000526613

Received: March 10, 2022
Accepted: August 10, 2022
Published online: August 18, 2022

Symptomatic Dermal Inclusion Cysts in Infants following Fetal Surgery for Myelomeningocele: Report of Two Cases and Review of the Literature

Benjamin J. Best[a] Huy Q. Truong[a] Andrew B. Foy[a, b]

[a]Department of Neurosurgery, Medical College of Wisconsin, Milwaukee, WI, USA; [b]Division of Neurosurgery, Children's Wisconsin, Milwaukee, WI, USA



Color version available online

Fig. 3. Intraoperative findings of patient in case 2. **a** Cyst was opened to reveal wax-like content (*asterisk*). **b** End of cord (*yellow triangle, cephalad end at left of image*), and cauda equina exposed after cyst resection (*yellow line, caudal end at right of image*).

Prenatal Myelomeningocele Closure Is Associated With Higher Risk Of Early Detethering Procedure For Tethered Cord- An NSBPR study

Hsin-Hsiao Scott Wang, Tanya Logvinenko, Benjamin Warf, Stuart Bauer, Erin McNamara, John Wiener, David Chu, Robin Bowman, Charles Rose, Heidi Castillo, Andrew Foy, Kathryn Smith, Alexander Van Speybroack, Carlos Estrada

Children's Wisconsin

MEDICAL COLLEGE OF WISCONSIN

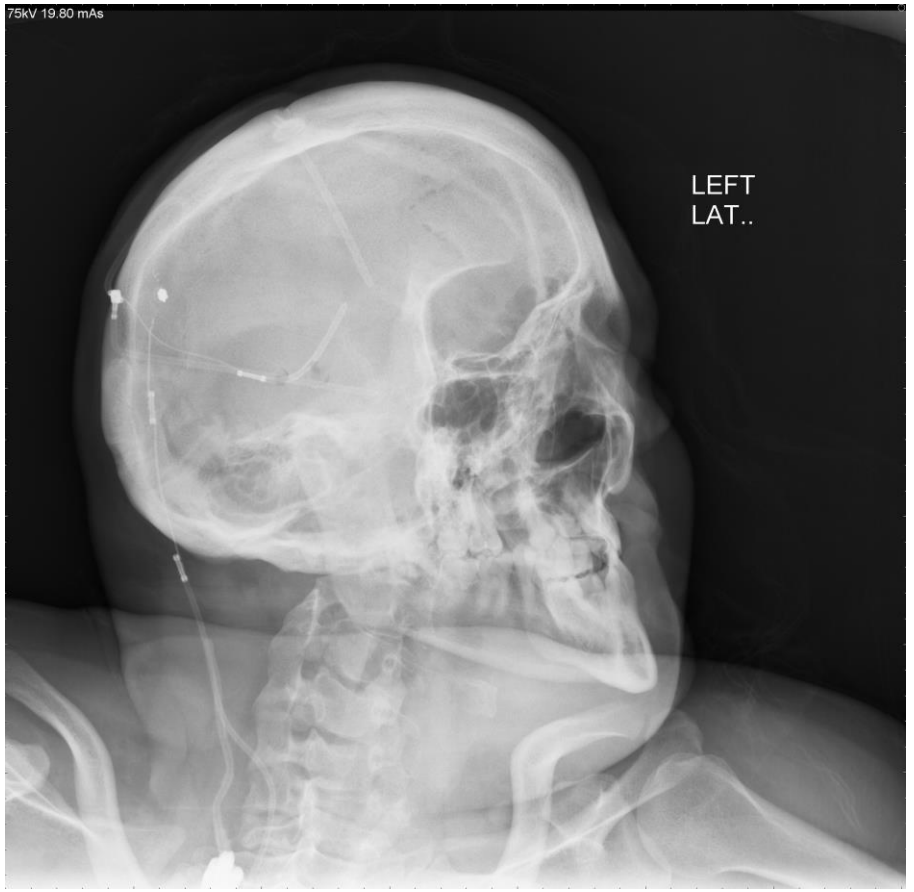
ETV/CPC

Children's Wisconsin

MEDICAL COLLEGE OF WISCONSIN

Other concerns

- Paucity of long-term outcomes
  - MOMS trial is relatively small, highly select population
  - MOMS trial is NOT a representative sample of children with spina bifida
  - Lack of outcome (especially long term) data beyond MOMS



Children's Wisconsin
MEDICAL COLLEGE OF WISCONSIN

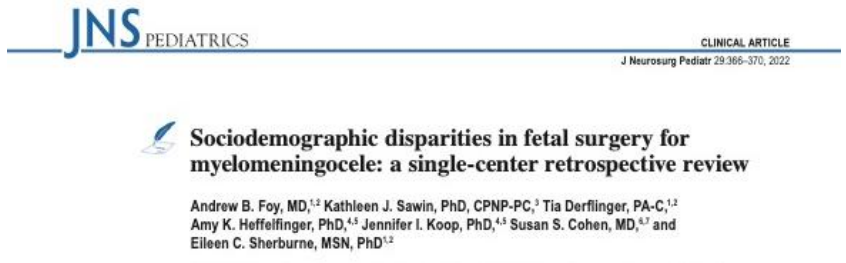
Disparities in access

- Disparities persist even after MOMS
- PLEASE REFER PATIENTS EARLY TO A FETAL CENTER

TABLE 1. Patient demographics and characteristics

Characteristic	Fetal Surgery (n = 23)	Postnatal Surgery (n = 182)	p Value
Sex, n (%) [95% CI]			0.746
F	11 (47.8) [26.8–69.4]	98 (53.8) [46.3–61.2]	
M	12 (52.2) [30.6–73.2]	84 (46.2) [38.8–53.7]	
Mean age, yrs (SD)*	6.00 (5.28)	9.99 (5.15)	0.002
Race & ethnicity, n (%) [95% CI]			0.058
Hispanic	1 (4.3) [0.1–21.9]	28 (15.4) [10.5–21.5]	
Non-Hispanic African American	0 (0.0) [0–14.8]	22 (12.1) [7.7–17.7]	
Non-Hispanic White	22 (95.7) [78.1–99.9]	125 (68.7) [61.4–75.3]	
Other	0 (0.0) [0–14.8]	7 (3.8) [1.6–7.8]	
Primary insurance, n (%) [95% CI]			<0.001
Commercial	23 (100.0) [85.2–100]	95 (52.2) [44.7–59.6]	
Medicaid	0 (0.0) [0–14.8]	80 (44.0) [36.6–51.5]	
Other	0 (0.0) [0–14.8]	7 (3.8) [1.6–7.8]	
Unknown	0	0	
DCI score			0.289
Mean (SD)	31.27 (29.87)	38.46 (30.76)	
Unknown, n	0	11	
Median household income by residential zip code			0.122
Mean (SD)	$66,507.35 ($21,123.30)	$59,133.01 ($17,762.90)	
Unknown, n	0	12	

* Age at the time of data collection.

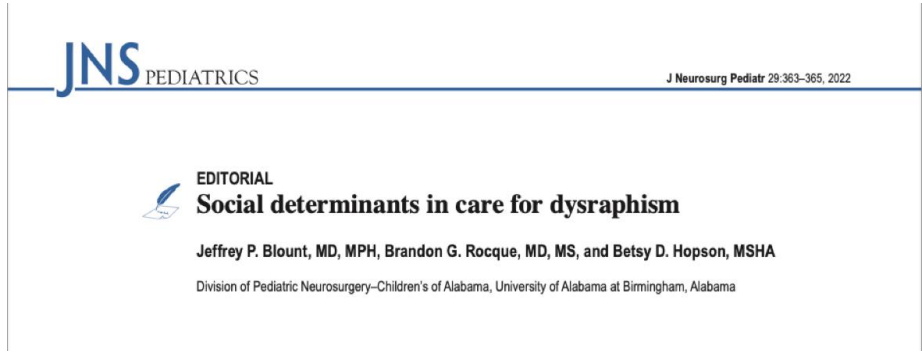

JNS PEDIATRICS

CLINICAL ARTICLE

J Neurosurg Pediatr 29:366–370, 2022

Sociodemographic disparities in fetal surgery for myelomeningocele: a single-center retrospective review

Andrew B. Foy, MD,[1,2] Kathleen J. Sawin, PhD, CPNP-PC,[3] Tia Derflinger, PA-C,[1,2] Amy K. Heffelfinger, PhD,[4,5] Jennifer I. Koop, PhD,[4,5] Susan S. Cohen, MD,[6,7] and Eileen C. Sherburne, MSN, PhD[1,2]


JNS PEDIATRICS

J Neurosurg Pediatr 29:363–365, 2022

EDITORIAL

Social determinants in care for dysraphism

Jeffrey P. Blount, MD, MPH, Brandon G. Rocque, MD, MS, and Betsy D. Hopson, MSHA

Division of Pediatric Neurosurgery–Children's of Alabama, University of Alabama at Birmingham, Alabama


JNS PEDIATRICS

CLINICAL ARTICLE

J Neurosurg Pediatr 29:643–649, 2022

Sociodemographic disparities as a determinant of fetal versus postnatal surgical myelomeningocele repair

Allie L. Harbert, MPH,[1] Randaline R. Barnett, MD,[2] Andrew L. Abumoussa, MD, MSc,[2] William H. Goodnight, MD, MSc,[3] Sue Tolleson-Rinehart, PhD,[4] and Carolyn S. Quinsey, MD[2]

Children's Wisconsin

MEDICAL COLLEGE OF WISCONSIN

Long term outcomes

- Lack of data about long term outcomes
  - Will patients treated with fetal surgery have the same outcome if not subjected to comprehensive monitoring, testing, treatment
- Guidelines for the management of spina bifida continue to lack high quality evidence
- Lifespan treatment in a comprehensive spina bifida clinic is vital

GUIDELINES FOR THE CARE OF PEOPLE WITH SPINA BIFIDA

SPINA BIFIDA ASSOCIATION

Children's Wisconsin

MEDICAL COLLEGE OF WISCONSIN

Children's Spina Bifida Clinic

- Medical director in 2019
- Started an iterative, multipronged quality improvement project
  - Goal: improve our ability to provide consistent, coordinated and high-quality care to our patients with spina bifida from the prenatal period until transition to adult care
  - Methods: Bundled approach of quality improvement (QI) initiatives similar to the bundled interventions to reduce hospital-acquired conditions.

SPINA BIFIDA ASSOCIATION

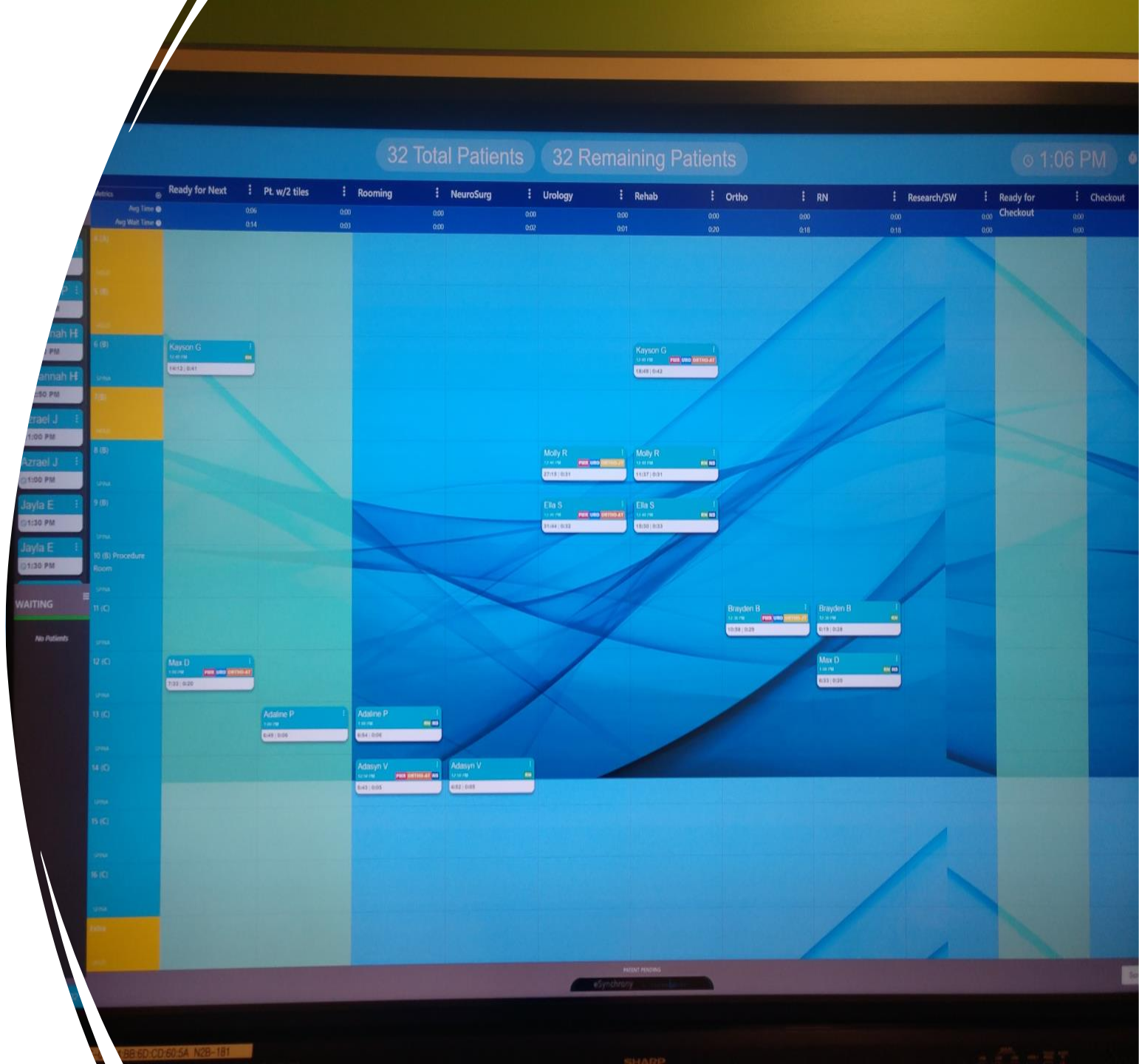
SPINA BIFIDA CLINIC CARE PARTNER

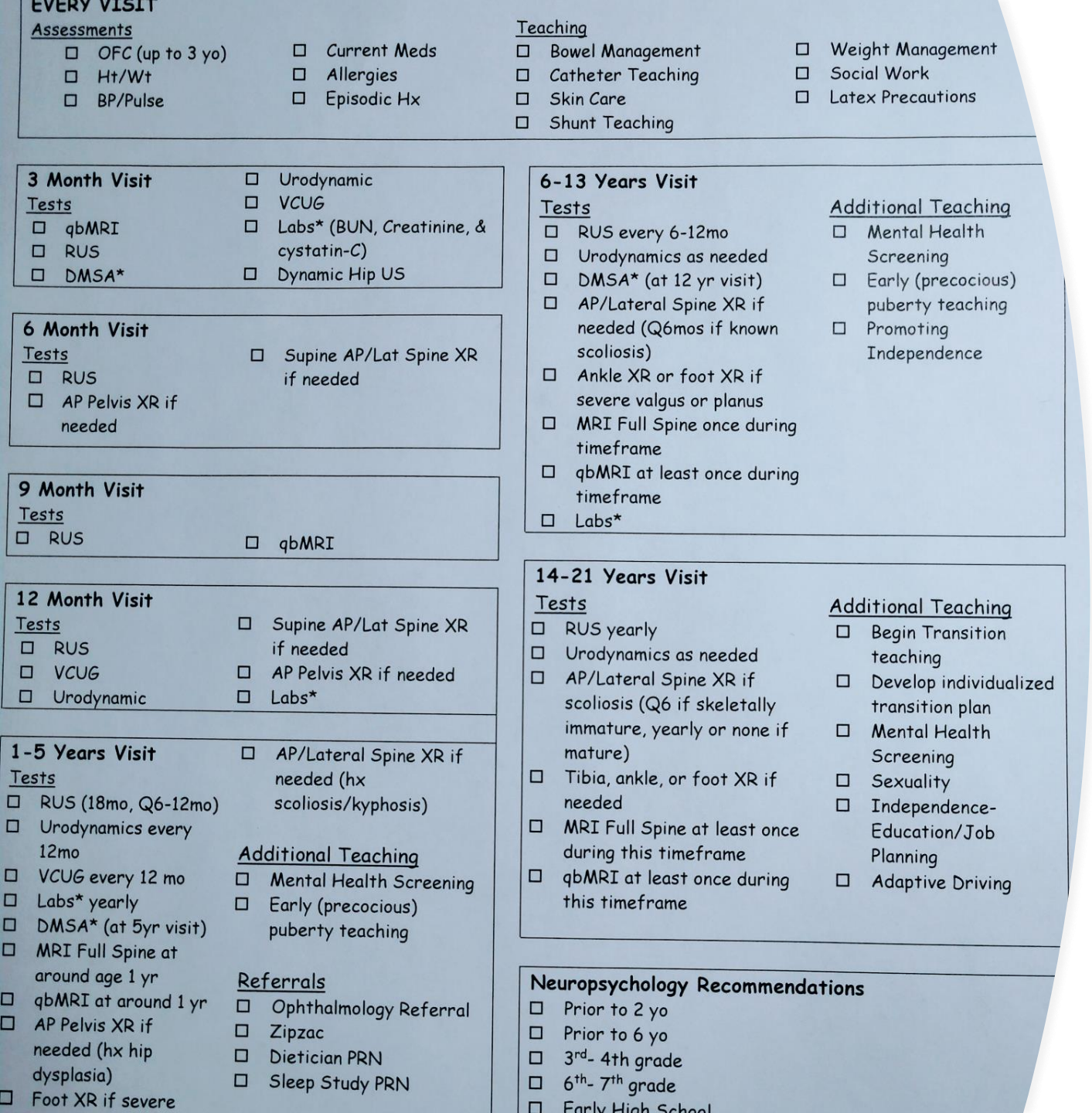
Children's Wisconsin

MEDICAL COLLEGE OF WISCONSIN

Spina Bifida Clinic Efficiency

- New clinic time and location
- Electronic tracking board
- Pre-clinic huddle
- Pre-clinic neuropsychology evaluation appointments





EVERY VISIT

Assessments
- ☐ OFC (up to 3 yo)
- ☐ Ht/Wt
- ☐ BP/Pulse
- ☐ Current Meds
- ☐ Allergies
- ☐ Episodic Hx

Teaching
- ☐ Bowel Management
- ☐ Catheter Teaching
- ☐ Skin Care
- ☐ Shunt Teaching
- ☐ Weight Management
- ☐ Social Work
- ☐ Latex Precautions

3 Month Visit

Tests
- ☐ qbMRI
- ☐ RUS
- ☐ DMSA*
- ☐ Urodynamic
- ☐ VCUG
- ☐ Labs* (BUN, Creatinine, & cystatin-C)
- ☐ Dynamic Hip US

6 Month Visit

Tests
- ☐ RUS
- ☐ AP Pelvis XR if needed
- ☐ Supine AP/Lat Spine XR if needed

9 Month Visit

Tests
- ☐ RUS
- ☐ qbMRI

12 Month Visit

Tests
- ☐ RUS
- ☐ VCUG
- ☐ Urodynamic
- ☐ Supine AP/Lat Spine XR if needed
- ☐ AP Pelvis XR if needed
- ☐ Labs*

1-5 Years Visit

Tests
- ☐ RUS (18mo, Q6-12mo)
- ☐ Urodynamics every 12mo
- ☐ VCUG every 12 mo
- ☐ Labs* yearly
- ☐ DMSA* (at 5yr visit)
- ☐ MRI Full Spine at around age 1 yr
- ☐ qbMRI at around 1 yr
- ☐ AP Pelvis XR if needed (hx hip dysplasia)
- ☐ Foot XR if severe
- ☐ AP/Lateral Spine XR if needed (hx scoliosis/kyphosis)

Additional Teaching
- ☐ Mental Health Screening
- ☐ Early (precocious) puberty teaching

Referrals
- ☐ Ophthalmology Referral
- ☐ Zipzac
- ☐ Dietician PRN
- ☐ Sleep Study PRN

6-13 Years Visit

Tests
- ☐ RUS every 6-12mo
- ☐ Urodynamics as needed
- ☐ DMSA* (at 12 yr visit)
- ☐ AP/Lateral Spine XR if needed (Q6mos if known scoliosis)
- ☐ Ankle XR or foot XR if severe valgus or planus
- ☐ MRI Full Spine once during timeframe
- ☐ qbMRI at least once during timeframe
- ☐ Labs*

Additional Teaching
- ☐ Mental Health Screening
- ☐ Early (precocious) puberty teaching
- ☐ Promoting Independence

14-21 Years Visit

Tests
- ☐ RUS yearly
- ☐ Urodynamics as needed
- ☐ AP/Lateral Spine XR if scoliosis (Q6 if skeletally immature, yearly or none if mature)
- ☐ Tibia, ankle, or foot XR if needed
- ☐ MRI Full Spine at least once during this timeframe
- ☐ qbMRI at least once during this timeframe

Additional Teaching
- ☐ Begin Transition teaching
- ☐ Develop individualized transition plan
- ☐ Mental Health Screening
- ☐ Sexuality
- ☐ Independence-Education/Job Planning
- ☐ Adaptive Driving

Neuropsychology Recommendations
- ☐ Prior to 2 yo
- ☐ Prior to 6 yo
- ☐ 3rd- 4th grade
- ☐ 6th- 7th grade
- ☐ Early High School

Clinical Care Checklist

- Providers review at each clinic visit
- Based on SBA Guidelines for Clinical Care
- Standardizes patient care
- Guides patient/family education

Children's Wisconsin

Medical College of Wisconsin

Team Engagement

- Clinical Dashboard
  - Updated quarterly
- Research/QI Dashboard
  - Summary of ongoing projects
- Quarterly Program Team Meetings
  - Outside of clinic time
  - Includes clinic team and others essential to our program such as researchers, ambulatory leadership, neuropsychology

Clinical Dashboard

- Goals
  - Transparency of care provided
  - Team engagement and accountability
  - Track care provided for administrative purposes/resources
  - Ensure consistent care
- Iterative process

Heal Children and Promote Wellness						
	Current period *Q3 2022*	**Year to date (YTD)** *Jan 1 – Sept 30*	**Variance from prior YTD**	**Status**	**Frequency Updated**	
Overall clinic volume					Quarterly	**Overall volume**: arrived/ completed appointments. **Distance patient**: unique patients for visits. **Prenatal:** data from FCC **fMMR elsewhere:** patients who had prenatal repairs elsewhere & transferred their care to CW **Other new patients to SB:** new patients joining our program **Newborn MCC closures:** closures at CW **Target:** Maintain from previous year
Distance patient volume					Quarterly	
Out of state						
Wisconsin >100 miles from Milwaukee campus						
Prenatal consult volume					Quarterly	
fMMR elsewhere					Quarterly	
Other new patients to SB					Quarterly	
Newborn MCC closures						
Care For and About Me						
	Current period *Q3 2022*	**Year to date (YTD)** *Jan 1 – Sept 30*	**Variance from prior YTD**	**Status**	**Frequency Updated**	**Imaging volume:** outpatient encounters with ultrasound, x ray, MR, fluoro, or nuc med
No show rate					Quarterly	
Imaging volume (% overall outpatient)					Quarterly	
Ultrasound						
X ray						
Magnetic Resonance						
Fluoro						
Nuclear Med						

Additional metrics:

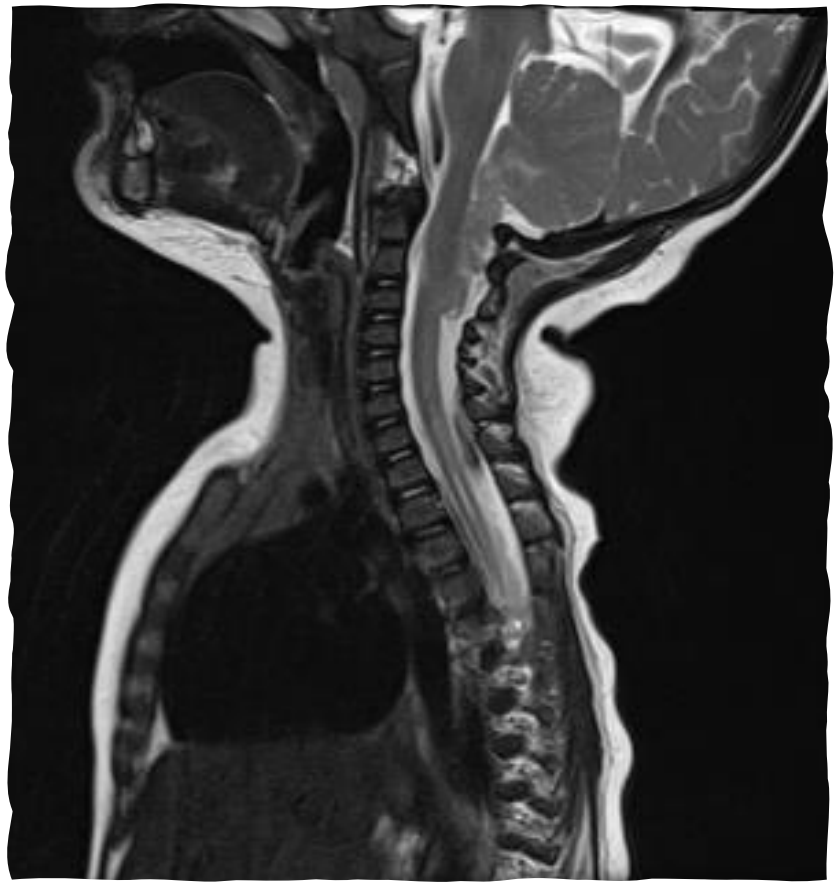
Surgical volume: Spina bifida patients (263) with at least one procedure with orthopedics, neurosurgery, PM&R or urology, total procedures performed, & MMC closures on newborns

	Q3 2022	**YTD 2022**	**Prior YTD**
Program patients with at least 1 surgical encounter			
Total procedures performed on program patients			
Newborn MMC closures			

Wisconsin

EDICAL COLLEGE OF WISCONSIN

Clinical Dashboard



- What did we learn?
  - 1.3-1.7% of ALL outpatient radiology studies throughout the hospital system are performed on SBC patients – a large volume of imaging on a small patient population
  - SBC patients accounted for ~100 operative procedures per year at Children's Wisconsin
  - A high no-show rate led to improvements in our pre-clinic processes, text and phone call reminders
  - Quarterly variations in imaging volume led us to standardize our approach to orthopedic and neurosurgical imaging, development of a clinical checklist to guide care

Children's Wisconsin

Medical College of Wisconsin

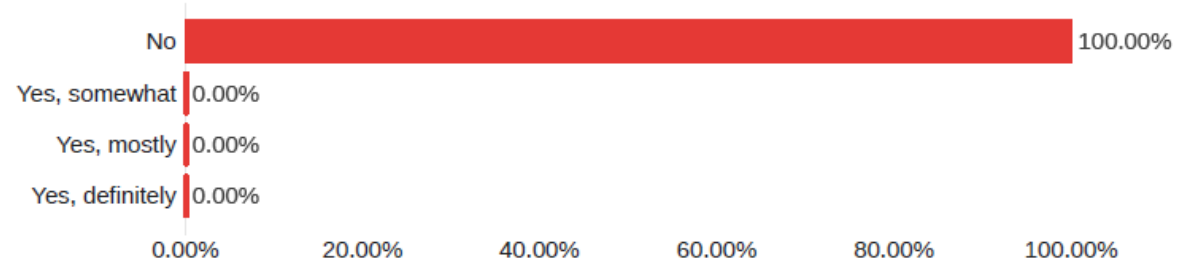
Spina Bifida Program Experience

- Program Coordinator Prenatal Visits
- Program Coordinator Inpatient Rounds
- Patient Satisfaction Survey

Patient satisfaction – Version 2.0

- What we learned
  - Consistency of caregivers and wait times are important to families
  - Often the comments are the most helpful for changing practices
  - Modified the survey to include 3 quantitative questions and 3 open-ended questions
  - Survey response rate has increased with time

Q2 - Did you experience a long wait time in between seeing care providers during your appointment?



Field	Min	Max	Mean	Standard Deviation	Variance	Responses
Did you experience a long wait time in between seeing care providers during your appointment?	1	1	1	0	0	4

Community Outreach

- Cross-Age Peer Mentorship Program
- Transition to adult spina bifida care
- Parent advisor
- Partnership with Spina Bifida Wisconsin

MEDICAL COLLEGE OF WISCONSIN

Results

- The enhanced clinic efficiency and promotion of the spina bifida program resulted in a **7.5% increase** in clinic visits from 2021 to 2022.
- Patient satisfaction scores **X=9.25/10**

Pre-Clinic Huddle	Completed prior to 63% of clinics, ≥4 specialty teams represented per huddle
Pre-Clinic Neuropsych	Pre-clinic slots utilized 29% Overall evaluations increased 24%
Transition Documentation	Completed on 75% of patients ≥17 years
Quarterly Team Meeting Attendance	18 participants per meeting, representation from all specialties and variety of disciplines (RNs, MDs, APPs, PhDs, social work)
SB RN Prenatal Visits	Met with 100% of prenatal patients
SB RN Inpatient Rounding	Rounded on 72% of admitted patients
Mentorship Program	Enrolled 22 families (11 matched pairs)
SBWI Representative in Clinic	Attended 75% of clinics Contacted 30 new families

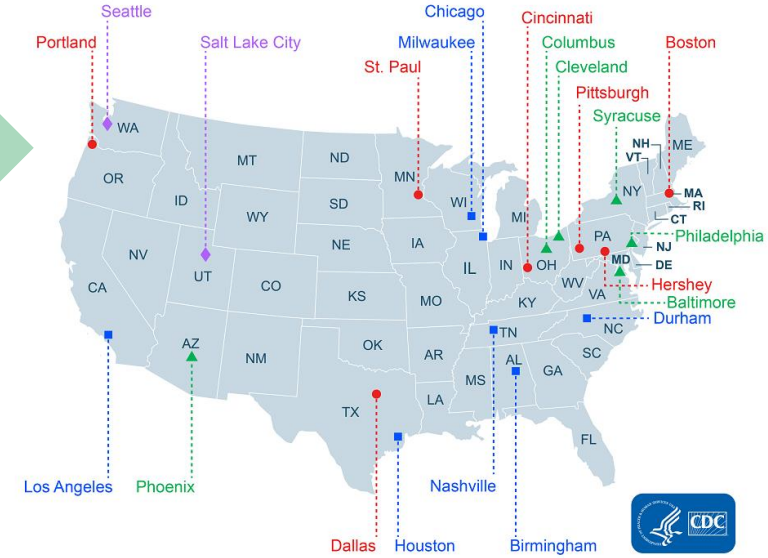
Children's Wisconsin

Medical College of Wisconsin

Research

- Spina Bifida Clinical Research Affinity Group at CW
  - Fortunate to have access to abundant neuropsychology resources
  - Cognitive outcomes remain understudied
  - Built clinic data flowsheet into Epic that can be exported and linked to cognitive data

- National Spina Bifida Patient Registry (NSBPR)
  - 10,000+ patients
  - CDC funded at Children's Wisconsin since inception (2009)
  - Have IRB approved access to all data from our institution



- UMPIRE urology protocol
  - CDC funded at CW since 2020
  - Elizabeth Roth leading standardization of urodynamics

- Children's Hospitals Neonatal Consortium (CHNC)
  - Fetal myelomeningocele study group

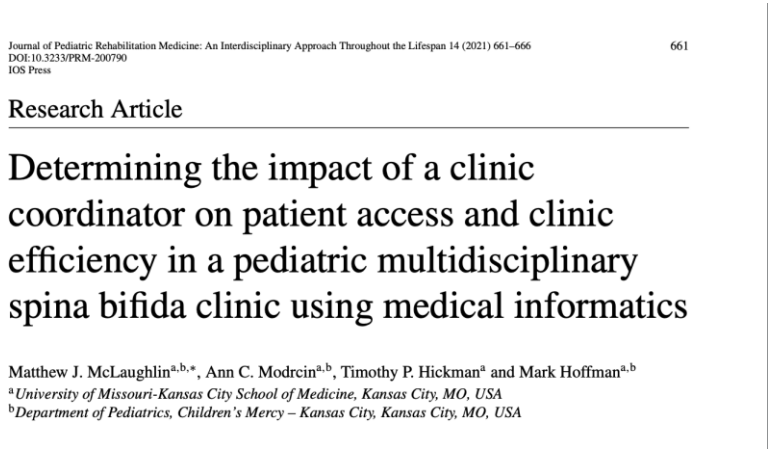
- NAFTNet registry

Children's Wisconsin

Medical College of Wisconsin

What's next

- Improved adult care
  - 60% of the spina bifida population is over the age of 18
  - Death from complications of spina bifida becoming more rare
  - Poorly coordinated and inconsistent transition and adult care is an ongoing issue around the country
  - Transition Committee of the AANS/CNS Pediatrics Section.



Journal of Pediatric Rehabilitation Medicine: An Interdisciplinary Approach Throughout the Lifespan 14 (2021) 661–666
DOI:10.3233/PRM-200790
IOS Press

Research Article

Determining the impact of a clinic coordinator on patient access and clinic efficiency in a pediatric multidisciplinary spina bifida clinic using medical informatics

Matthew J. McLaughlin[a,b,*], Ann C. Modrcin[a,b], Timothy P. Hickman[a] and Mark Hoffman[a,b]
[a]*University of Missouri-Kansas City School of Medicine, Kansas City, MO, USA*
[b]*Department of Pediatrics, Children's Mercy – Kansas City, Kansas City, MO, USA*

Children's Wisconsin

MEDICAL COLLEGE OF WISCONSIN

Acknowledgements

Thank you to all of the clinicians in the spina bifida program for supporting these QI initiatives, together we are improving the health and quality of life for children and youth with spina bifida.

Questions

Please reach out with any questions

afoy@mcw.edu

C: 414-520-8430

@abfoy

Children's Wisconsin

MEDICAL COLLEGE OF WISCONSIN