AROUND THE NETWORK

2020 NBDPN Annual Meeting
March 9, 2020

• Achievements and Next Adventures
• Business Update
• National Standards for Birth Defects Surveillance
• Multi-state Data Collaborations
• NBDPN Awards
Achievements and Next Adventures

Mahsa Yazdy, PhD
NBDPN Immediate Past-President
Massachusetts Department of Public Health

Achievements!

Folic Acid Fast Facts

- Folic acid is a B vitamin that our body uses to make new cells. Multivitamins are a great source of folic acid.
- It is recommended that women take 400 micrograms (mcg) of folic acid every day.

BIRTH DEFECTS SURVEILLANCE SYSTEMS

- Tips 1
- Consejo 1

BIRTH DEFECTS PREVENTION NETWORK

- Learn how you can participate in World Birth Defects Day: www.CDC.gov/nccds/birthdef... #WorldBDDay #ManyBirthDefectsVoice @CDC_NCCEDD

Congenital Heart Disease Review: Follow the Blood

MD, MPH

Children's Hospital of Boston
Achievements!

• Utilizing website functions to support our work
  • Elections, meeting registration, abstract submission, poster judging, nominations for awards, social event, and silent auction
• NBDPN & CDC leadership regular meetings
• Representation on Congenital Heart Public Health Consortium
  • Represent Network at strategic planning meeting
• Partnering with Society for Birth Defects Research and Prevention
  • The Challenge of Substance-Exposed Newborns
  • Communicating with others: What is a teratogen?
  • Upcoming webinar in May with Dr. Kancherla

Achievements!

• NBDPN has signed onto 7 letters/appeals, e.g.:
  • A letter requesting the Liaison Committee on Medical Education formally require content on developmental disabilities in the standards for accreditation of medical education programs
  • A letter supporting the Vaccine Awareness Campaign to Champion Immunization Nationally and Enhance Safety (VACCINES) Act of 2019
Achievements! ...Strategic Planning

• **Goal I:** Strengthen NBDPN governance to ensure effectiveness and sustainability
  - Established Governance Workgroup
  - Improving our financial accounting practices
  - Maintaining target number of members
    - All paid in full (~200)
    - Improved invoicing and timeliness of group payments
    - Created follow-up campaign for dues payment
    - More on membership shortly....

Achievements! ...Strategic Planning

• **Goal II:** Promote stewardship and utility of birth defects data
  - Developed technical tools
  - Participated in our partners’ meeting and events
    - Co-sponsored 3 webinars with Society for Birth Defects Research and Prevention
    - Presentation on NBDPN at International Clearinghouse for Birth Defects Surveillance and Research Meeting
  - March of Dimes Peristats published using 2018 state annual data
  - Many multi-state projects
Achievements! ...Strategic Planning

**Goal III:** Strengthen internal and external promotion and communication activities

- Regularly surveying members to understand members needs
  - Will hear about more shortly....
- Measuring the reach and effectiveness of communication tools
- Leveraging relationships and expertise among members, affiliates, and partners

Next Adventures for Strategic Planning

- Strategic Planning Group meeting regularly
  - Plan next iteration
- The Network is becoming more independent
- Functional reorganization in phases

→ Education and Outreach
→ NTD Surveillance/ Folic Acid Education
→ Publication and Communications
Next Adventures for Strategic Planning

• Revision of bylaws
  • Summer 2020: out for comment and vote
• Continue reorganization into functional groups
• Establish a more traditional Board
  • Planned vote on board members in Fall 2020

Where most of the magic happens...

COMMITTEES!!
Annual Meeting Committee

Virtual meeting in 2019
• Over 300 registrants from 40 states, the Department of Defense, DC, Puerto Rico and South Africa.
• Sessions on analytic methodologies, surveillance for chromosomal defects, the use of electronic health records, and much more!

This meeting!
• Record number of abstracts! 51
• Developing partnerships
  • Partners Luncheon
  • Facilitate pre-meeting meet up with Organization of Teratology Information Specialists (OTIS)
  • March of Dimes Advocacy Training Webinar

Membership & Elections Committee

• Oversee annual elections process
  • 2019 elections utilized website for nominations and elections

• Conducted 2019 survey of membership

• Continued to manage Mentorship Program
  • Held five calls with program managers

• Processed and tracked membership applications/ renewals
  • Big push to clean up membership roster

• Process for requests from those unaffiliated with a state/ known program

• Compiled membership benefits list and how to best promote NBDPN
Membership & Elections Committee

Next Adventures:

- Conduct outreach to attendees who are not members
- Consider mentoring calls for those in other positions or functional areas
- Identify strategies to increase and retain actively engaged membership

Surveillance Guidelines & Standards Committee

ICD-10-CM and Birth Defects Workgroup

- Timeline of ICD-10-CM changes
- Code translation from ICD-9-CM to ICD-10-CM
- ICD-9 to ICD-10 transition guidance

Technical Tools Workgroup

- 2018 Preconference training: Medical Records Abstraction 101
- Assisted with creating the "Follow the Blood" Webinar
- Currently working on two abstracting training webinars
Surveillance Guidelines & Standards Committee

**HL7/HER Workgroup**
- Currently collaborating with Altarum to create electronic birth defect specification reporting standards

**Neonatal Abstinence Syndrome Workgroup**
- Newly created workgroup on how Birth Defects Surveillance Programs can assist with and improve surveillance of NAS

**Data Quality and Standards Workgroup**
- Will hear about shortly....

**Next Adventures:**
- Reorganization of working groups
- Focus on revisions of Birth Defects Surveillance Guidelines document

State Data Committee

**ACHIEVEMENTS & Next Adventures**

- Will hear about shortly....

Chair: Dominique Heinke (MA)
Ethical, Legal, and Social Issues (ELSI) Committee

ACHIEVEMENTS & Next Adventures

• Last big effort was preparing a HIPAA guidance document a few years ago
• Working to bring on a co-chair
• Redesigning ELSI to better meet Network needs and align with strategic planning
• Committee has come together and brainstormed future ELSI activities, so more to come

Chair:
Dianna Contreras (AZ)

NTD Surveillance / Folic Acid Education

ACHIEVEMENTS

• Developed Folic Acid Awareness Week (FAAW) materials
  • Tips for states on how to promote FAAW on social media
  • 2020: >1700 page views!
• Multi-state project looking at spina bifida lesion level changes before and after folic acid fortification
  • 6 states participating
  • Abstracts submitted to Society for Birth Defects Research and Prevention Annual Meeting and planned for the International Clearinghouse of Birth Defects Surveillance and Research Meeting

Next Adventures:
• Merging of committees

Chairs:
Barbara Frohnert (MN)
Lindsay Overman (AR)
Publications and Communications Committee

- Newsletter email
  - Most clicks: the ICD9 to ICD10 transition document
- Articles of Potential Interest (API) Reboot
  - In newsletter and nbdpn.org
- Social media
  - Events
  - Research
  - Messaging

1,400 Followers!

Next Adventures:
- Merging of committees

Chair: Joan Ehrhardt (MI)

Education and Outreach Committee

- Produced messaging for each day of Congenital Heart Defect Awareness Week
- Support social media for World Birth Defects Day
- Coordinated the Birth Defects Prevention Month toolkit
  - > 3,000 views of Toolkit webpage!

Next Adventures:
- Merging of committees

Chair: Mary Knapp (NJ)
Birth Defects Prevention Month 2020

31 posts
8,440 views!

7 tweets
8,590 impressions!

TWEETREACH SNAPSHOT
#Best4youBest

ESTIMATED REACH

3,241,627

ACCOUNTS REACHED

1

ACTIVITY

1,500 TWEETS

387 CONTRIBUTORS

8 DAYS

Bilingual twitterchat by MOD

NBDPN’s Next Adventures...

National Birth Defects Prevention Network

Surveillance  Research  Prevention
NBDPN's Next Adventures…

• **We hear you!**
  • Working to increase transparency
    • Publishing committee and EC minutes online
    • Creating calendar of meetings/events
  • Developing policies and procedures
  • Engaging new members and improving new member experience
  • Fostering a culture of inclusivity and increasing member engagement

NBDPN is powered by its volunteers!
Get involved!

• Join a committee!
  • Mon 12:30-1:30
    • Ethical, Legal, and Social Issues (ELSI) Committee
    • Data Committee Meeting
    • Communications and Health Promotions
      • P&C, E&O, NTD/FA
  • Tues 12:30-1:30
    • NTD Surveillance/Folic Acid Education Committee
    • Surveillance, Guidelines and Standards (SGSC) Committee

• Meet-Up Match-Up
  • Talk to colleagues about your favorite topic

• Meet your Presidents
  • Monday evening at 6:30pm at the Socci bar

Send comments/suggestions to the Presidents
BUSINESS UPDATE

Sarah A. Henry, MPH
NBDPN Secretary-Treasurer
Minnesota Department of Health

Operating Costs

• Operating costs for 2020 are about $10,000
  • Includes things such as:
    • Accountant
    • Insurance
    • Incorporation fees
    • Website
    • Supplies
  • Does not include:
    • Annual Meeting
    • Strategic Planning
Membership is Important!

- Membership dues are our main source of funding
  - Dues cover a majority of operating costs, but not all

- Membership dues are $60
  - Run from July 1 – June 30

- To join as a member:
  
  *Submit your registration for membership on-line today!*  
  Download or print the NBDPN flyer.

Donations are also important!

- In 2019 the Network received $706 in donations
  - Includes a $406 donation from BJG Electronics, Inc.

- In 2020 the Network has received $365 in donations, including:
  - A $265 donation from Michael Peters
  - A $100 donation from the Association of University Centers on Disabilities (AUCD), for this meeting

- Ways to donate:
  - Directly to the Network: website, registration desk, check, feed the pig
  - Amazon Smile
  - Purchasing sale items: tumblers!
  - Silent auction
Website Usage: Elections

Nominations for the 2020 NBDPN elected offices have been finalized. The candidates and their biographical profiles are listed below. Click on the following link to open the position descriptions.

President Elect

Big Bird

Big Bird is a character on the children's television show Sesame Street. He is the tallest character on the show and is known for his love of playing and learning. He speaks in a nonsense language that children can relate to, and he enjoys teaching them about numbers, colors, and more. His bright yellow feathers and cheerful personality make him a favorite among viewers.

Mickey Mouse

Mickey Mouse is a classic cartoon character created by Walt Disney. He is known for his iconic black pants, white gloves, and bright red bow tie. Mickey Mouse first appeared in the short film Steamboat Willie (1928), the first cartoon with synchronized sound. Since then, he has starred in hundreds of films and has become a beloved icon in the world of animation.

Website Usage: Award Nominations

Provide information about the Agency/Program/Organization, below:

Lead Contact name *

Lead Contact phone number *

Lead Contact email *

Name of Project or Activity for which the nomination is being made *

Name(s) of Main Contributing Agencies, Organizations, or Programs (e.g. March of Dimes, Spina Bifida Association, State or Private University; State or Local Health Department) *

National Birth Defects Prevention Network
Website Usage: Annual Meeting Registration

Agenda and Session Options

Sunday Training - 1:00PM-5:00PM
Openings no longer available for:
Parenting for Heart Health Workshop: Preventing Birth Defects

Monday Plenary - 8:00AM-12:00PM
- Welcome Session - 8:00AM-10:00AM:
  Building your state collaborations with your MCH Partners/ Collaborating for Moms and Babies - 9:00AM-10:00AM;
  Break - 10:00AM-10:15AM;
  Around the Network - 10:15AM-12:00PM

Monday Committee Meetings - 12:30PM-1:30PM
- NBDPN Ethical, Legal, and Social Issues (ELSI) Committee
  The Committee recommends minimum standards policy guidelines for NBDPN members to use when establishing birth defect public health surveillance, research, and prevention activities.
- NBDPN Education and Outreach (E&O) Committee
  Families may need assistance with educational materials describing particular birth defects, intervention strategies, services available in their state, parent support groups, appropriate medical teams specific to their child's needs, genetic counseling, etc. This Committee develops content for the annual Birth Defects Prevention Month educational packet.

Website Usage: Poster Abstracts

Please select the Category that best fits your submission...

Category Selection

- 1-CASE ASCERTAINMENT
  Innovative approaches to, use of electronic health records, surveillance, surveillance methodologies, pediatric disease registries, quality assurance/quality control, program evaluation, multi-state collaborative projects
- 2-BIRTH DEFECTS RISK FACTORS
  Prescription and over-the-counter medication, alcohol and illegal drugs, infectious agents, hazardous substances, environmental or genetic risk factors, maternal risk factors such as diabetes and obesity, fertility treatments
- 3-BIRTH DEFECTS RATES AND TRENDS
  Graphical presentation of data, statistical assessment (simple or complex), cluster analyses, meta-analyses, multilevel analysis, use of surveillance data to measure outcomes
- 4-PREVENTION, INTERVENTION, AND PUBLIC POLICY
  Evaluation of prevention or intervention activities, use of birth defect registries to link to services, preconception care, state based prevention programs, improving access to services, health services utilization, analysis of public policy, analysis of public awareness, use of data to affect public policy
- 5-NATIONAL BIRTH DEFECTS PREVENTION STUDY
Membership Numbers – Over Time

Number of Members Invoiced, by Year

New Members Over Time

Number of Members Who Joined, by Year
Current Members – Organization Type

- State Government: 55%
- University: 14%
- Non-Profit: 5%
- Federal Government: 4%
- Local Government: 3%
- Private Agency: 2%
- Other: 5%
- No Information: 10%

Current Members: Geography
Current Members: by Year Joined

![Bar chart showing current members by year joined NBDPN](chart.png)

Membership Benefits

- Hold officer positions or serve as committee leads
- Mentoring Program
- Serve on committees
- Peer assistance from other Network members
- Members only area on the website
- Support Network Operations
Members Only Area of Website

- Access webinars
  - Follow the Blood
  - March of Dimes Peristats
- Analytic resources and tools
- Update your contact information
- Search for Members

2019 Membership Survey

- Survey was sent out in Spring 2019
- 69 responses received (32% of members at the time)
- First membership survey since 2012
2019 Membership Survey Continued

- 63% work for a State Health Department
- 53% handle 2 or more roles in his/her birth defects programs
- 59% split his/her time between birth defects and other programs
2019 Membership Survey Continued

Involvement in the Network
• Most respondents (55%) were currently either a committee chair/co-chair, participating in committee calls or working actively on a NBDPN committee
• Eleven respondents (16%) were not currently active

How the Network can help members with surveillance activities
• More training opportunities (54%)
• Mentoring opportunities (23%)
• Continue to provide resources (e.g. annual reports, data briefs, guidelines, etc.) (88%)

2019 Membership Survey Continued
2019 Membership Survey - Conclusion

• We hear you
• We appreciate you and everything you do for the Network
• Feedback is accepted and appreciated at any time
  • nbdpn@nbdpn.org
  • http://bit.ly/NBDPNpresidents

Thank you!

The following individuals have put in tremendous work over the last year with membership, the website, and other day-to-day operations
• Joan Ehrhardt
• Kim Hauser
• Jennifer Isenburg
• Philip Lupo
• Brennan Martin
• Amy Nance
• Sam Viner-Brown
• Mahsa Yazdy
NATIONAL STANDARDS FOR BIRTH DEFECTS SURVEILLANCE

Nina Forestieri, MPH
For the SGSC Standards Workgroup

Birth Defects Surveillance Standards

What are the key factors and attributes that we need to be similar across programs?
DQ Assessment

- Beginning in 2015, data quality assessments have been collected from programs each year at the same time as the annual report (late spring)

- A national summary report as well as program-specific summary reports are generated and sent out to programs
Data Quality Assessment Tool

Completeness
- DQ1.1: Types of data sources used systematically and routinely to identify potential cases at a population-based level
- DQ1.2: Birth defects included using standard NBDPN case definitions
- DQ1.3: Pregnancy outcomes included
- DQ1.4: Systematic and routine identification of cases during ascertainment period (age of diagnosis)
- DQ1.5: Data elements collected

Timeliness
- DQ2.1: Time of case data completion for NBDPN "core" list
- DQ2.2: Time of case data completion for NBDPN "recommended" list

Accuracy
- DQ3.1: Data quality procedures for verification of cases diagnosis
- DQ3.2: Scope of birth defects verified
- DQ3.3: Level of expertise for individuals who perform case diagnosis verification
- DQ3.4: Database quality assurance process

Level 1: Rudimentary
Level 2: Essential
Level 3: Optimal

DQ Summary Results Report
DQ Summary Results Report


<table>
<thead>
<tr>
<th>Year</th>
<th>Completeness Mean</th>
<th>Timeliness Mean</th>
<th>Accuracy Mean</th>
<th>Overall Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>2015</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
</tr>
<tr>
<td>2016</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
</tr>
<tr>
<td>2017</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
</tr>
<tr>
<td>2018</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
</tr>
<tr>
<td>2019</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
</tr>
</tbody>
</table>

*Figure includes only programs that consistently submitted forms in the five most recent years.

All Performance Measures (2019 results)

Summary Performance on Data Quality Measures (2019)
Data Quality Indicator Survey

- In 2019, we solicited feedback from programs on the feasibility and usefulness of adding statistical measures to the NBDPN DQ Tool
  - E.g. NTD prevalence; spina bifida to anencephaly ratio
- 35 programs responded to the survey
  - 74% agreed there would be value in adding statistical measures to the DQ Tool
  - Respondents thought prevalence indicators would be most feasible and useful

Next Steps

- Review and improve the Data Quality Standards
  - Based on feedback from the data quality indicator survey, consider the addition of statistical measures as a way to help validate quality measures reported by programs
  - Determine how NBDPN can better support programs
    - E.g., DQ Toolbox that sites could use to assess and improve their data quality
Next Steps

- Develop Data Utility Standards
  - Monitoring
    - Basic monitoring, data availability and dissemination, data expansion/augmentation
  - Public health practice
    - Referral to services, prevention and education/outreach, community investigations
  - Research

Thank you!
MULTI-STATE DATA COLLABORATIVE PROJECTS

Dominique Heinke, ScD
She/Her/Dr
On behalf of the NBDPN Data Committee

Why are multi-state collaborations key to NBDPN?
NBDPN Mission

- **Improve access** to information
- **Increase collaboration** within the birth defects community
- **Advance science** through surveillance

Multi-state collaborations help us reach these goals
Individual States

What you think your data will be like

What it’s actually like

Multi-state Collaborations

Unsatisfyingly small slice

Now that’s A SLICE!
Multi-state Collaborations

Reports

National Estimates
Annual Report
Data Brief

Call for Data

Data Repository
Focused Projects

Special Projects

Reports
Data Briefs

Critical Congenital Heart Defects
- Trisomies: 62
- Oral Clefts: 62
- Variation in Prevalence Estimates: 41
- Microcephaly: 47

Eye & Ear Defects
- Gastrointestinal Defects
- Abdominal Wall Defects

2010 2015 2020

2019 Data Brief

Population-based birth defects data in the United States, 2012–2016: A focus on abdominal wall defects

Erin B. Stallings, Jennifer L. Isenburg, Tyiesha D. Short, Dominique Heinke, Russell S. Kirby, Paul A. Romitti, Mark A. Canfield, Leslie A. O’Leary, Rebecca F. Liberman, Nina E. Forestieri, Wendy N. Nembhard, Theresa Sandidge, Eirini Nestoridi, Jason L. Salemi, Amy E. Nance, Kirstan Duckett, Glenda M. Ramirez, Xiaoyi Shan, Jing Shi, Philip J. Lupo... See fewer authors
### Table 2
Abdominal wall defect counts, prevalence, and 95% confidence intervals for 30 US population-based surveillance programs, 2012–2016 (prevalence per 10,000 live births)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Gastrochisis</th>
<th></th>
<th>Omphalocele</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Count</td>
<td>Prevalence</td>
<td>95% CIb</td>
<td>Count</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>5,349</td>
<td>4.3</td>
<td>4.1–4.4</td>
<td>2,601</td>
</tr>
<tr>
<td><strong>Case ascertainment methodology</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Active case finding</td>
<td>2,677</td>
<td>4.7</td>
<td>4.6–4.9</td>
<td>1,262</td>
</tr>
<tr>
<td>Passive case finding</td>
<td>2,672</td>
<td>3.9</td>
<td>3.7–4.0</td>
<td>1,339</td>
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<tr>
<td><strong>Maternal race/ethnicity</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White, non-Hispanic</td>
<td>2,857</td>
<td>4.3</td>
<td>4.2–4.5</td>
<td></td>
</tr>
<tr>
<td>Black, non-Hispanic</td>
<td>632</td>
<td>3.2</td>
<td>3.0–3.5</td>
<td>627</td>
</tr>
<tr>
<td>Hispanic</td>
<td>1,524</td>
<td>5.0</td>
<td>4.8–5.3</td>
<td>543</td>
</tr>
<tr>
<td>Asian or Pacific Islander, non-Hispanic</td>
<td>105</td>
<td>1.6</td>
<td>1.3–1.9</td>
<td>80</td>
</tr>
<tr>
<td>American Indian or Alaska Native, non-Hispanic</td>
<td>71</td>
<td>7.2</td>
<td>5.6–9.1</td>
<td>18</td>
</tr>
</tbody>
</table>

### Table 3
Abdominal wall defect counts, percentages, and 95% confidence intervals for 30 US population-based surveillance programs, 2012–2016

<table>
<thead>
<tr>
<th>Variable</th>
<th>Gastrochisis (n = 5,349)</th>
<th></th>
<th>Omphalocele (n = 2,601)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Count</td>
<td>Percent</td>
<td>95% CIc</td>
<td>Count</td>
</tr>
<tr>
<td><strong>Gestational age (weeks)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20–23 weeks</td>
<td>57</td>
<td>1.1</td>
<td>0.8–1.4</td>
<td>127</td>
</tr>
<tr>
<td>24–27 weeks</td>
<td>59</td>
<td>1.1</td>
<td>0.8–1.4</td>
<td>102</td>
</tr>
<tr>
<td>28–33 weeks</td>
<td>565</td>
<td>10.6</td>
<td>9.8–11.4</td>
<td>368</td>
</tr>
<tr>
<td>34–36 weeks</td>
<td>2,510</td>
<td>46.9</td>
<td>45.6–48.3</td>
<td>531</td>
</tr>
<tr>
<td>37+ weeks</td>
<td>2,096</td>
<td>39.2</td>
<td>37.9–40.5</td>
<td>1,428</td>
</tr>
<tr>
<td><strong>Birth weight (grams)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very low birth weight (less than 1,500 g)</td>
<td>291</td>
<td>5.4</td>
<td>4.8–6.1</td>
<td>370</td>
</tr>
<tr>
<td>Low birth weight (1,500–2,499 g)</td>
<td>2,785</td>
<td>52.1</td>
<td>50.7–53.4</td>
<td>629</td>
</tr>
<tr>
<td>Normal birth weight (≥2,500 g)</td>
<td>2,170</td>
<td>40.6</td>
<td>39.2–41.9</td>
<td>1,426</td>
</tr>
<tr>
<td><strong>Plurality</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Singleton</td>
<td>5,146</td>
<td>96.2</td>
<td>95.7–96.7</td>
<td>2,400</td>
</tr>
<tr>
<td>Twin or multiple</td>
<td>117</td>
<td>2.2</td>
<td>1.8–2.6</td>
<td>137</td>
</tr>
<tr>
<td><strong>Pregnancy outcome</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Live births</strong></td>
<td>5,181</td>
<td>94.3</td>
<td>93.4–95.0</td>
<td>1,237</td>
</tr>
<tr>
<td>Non-live births</td>
<td>190</td>
<td>5.6</td>
<td>4.9–6.5</td>
<td>293</td>
</tr>
</tbody>
</table>
### Table 4
Co-occurring birth defects by organ system for abdominal wall defects from 15 US population-based active case-finding surveillance programs, 2012–2016

<table>
<thead>
<tr>
<th>ICD' code groups</th>
<th>Gastrochisis (n = 2,677)</th>
<th>Omphalocele (n = 1,262)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Count</td>
<td>Percent</td>
</tr>
<tr>
<td>Congenital anomalies (740–759)/congenital malformations, deformations and chromosomal abnormalities (Q00-Q99)³</td>
<td>898</td>
<td>33.6</td>
</tr>
</tbody>
</table>

Cited over 1300 times!
Multi-state Collaborative Projects

The National Birth Defects Prevention Network helps facilitate collaborative projects. Abstracts of publications from the Network’s numerous collaborative projects can be found here.


Published Multi-state

The National Birth Defects Prevention Network helps facilitate collaborative projects. Abstracts of publications from the Network’s numerous collaborative projects can be found here.
Published Multi-state

Prevalence and descriptive epidemiology of infantile hypertrophic pyloric stenosis in the United States: A multistate, population-based retrospective study, 1999-2010

Renuka Kapoor, Vijaya Kancherla, Yanyan Cao, Jacob Oleson, Jonathan Suh, Mark A Canfield, Charlotte M Druschel, Russell S Kirby, Robert E Meyer, Paul A Romitti ... See fewer authors

Study of selected birth defects among American Indian/Alaska Native population: A multi-state population-based retrospective study, 1999-2007

Lisa K Marengo, Timothy J Flood, Mary K Ethen, Russell S Kirby, Sarah Fisher, Glenn Copeland, Robert E Meyer, Julie Dunn, Mark A Canfield, Tom Anderson, Del Yazzie, Cara T Mai, for the National Birth Defects Prevention Network ... See fewer authors

Prevalence of selected birth defects by maternal nativity status, United States, 1999-2007

Russell S Kirby, Cara T Mai, Martha S Wingate, Teresa Janevic, Glenn E Copeland, Timothy J Flood, Jennifer Isenberg, Mark A Canfield, for the National Birth Defects Prevention Network ... See fewer authors

Data Repository

Study of selected birth defects among American Indian/Alaska Native population: A multi-state population-based retrospective study, 1999-2007

Lisa K Marengo, Timothy J Flood, Mary K Ethen, Russell S Kirby, Sarah Fisher, Glenn Copeland, Robert E Meyer, Julie Dunn, Mark A Canfield, Tom Anderson, Del Yazzie, Cara T Mai, for the National Birth Defects Prevention Network ... See fewer authors
TABLE 2  Prevalence, crude, and adjusted prevalence ratios for selected birth defects among American Indian/Alaska Native by Hispanic ethnicity, 12 U.S. Birth Defects Surveillance Programs, 1999–2007

<table>
<thead>
<tr>
<th>Defect</th>
<th>Non-Hispanic Whitea (referent)</th>
<th>Non-Hispanic American Indian/Alaska Nativea</th>
<th>Any American Indian/Alaska Native, regardless of Hispanic ethnicitya</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Cases (95% CI)</td>
<td>Cases (95% CI)</td>
<td>cPR (95% CI)</td>
</tr>
<tr>
<td>Encephalocele</td>
<td>444 (0.56–0.67)</td>
<td>13 (0.75–2.41)</td>
<td>2.29 (1.25–3.80)</td>
</tr>
<tr>
<td>Anotia/microtia</td>
<td>843 (1.09–1.75)</td>
<td>43 (3.38–6.29)</td>
<td>3.99 (2.89–5.34)</td>
</tr>
<tr>
<td>Cleft lip +/- cleft palate</td>
<td>6,955 (9.44–9.89)</td>
<td>185 (17.19–22.98)</td>
<td>2.08 (1.79–2.40)</td>
</tr>
<tr>
<td>Cleft palate alone</td>
<td>4,573 (6.17–6.54)</td>
<td>60 (4.97–8.39)</td>
<td>1.03 (0.79–1.31)</td>
</tr>
<tr>
<td>Gastrochisis</td>
<td>1967 (2.96–3.24)</td>
<td>59 (2.52–8.84)</td>
<td>2.21 (1.69–2.83)</td>
</tr>
<tr>
<td>Upper limb reductions</td>
<td>1985 (2.64–2.68)</td>
<td>40 (3.10–5.91)</td>
<td>1.57 (1.31–2.12)</td>
</tr>
<tr>
<td>Lower limb reductions</td>
<td>1,079 (1.41–1.59)</td>
<td>24 (1.67–3.88)</td>
<td>1.74 (1.13–2.54)</td>
</tr>
<tr>
<td>Trisomy 18</td>
<td>1,168 (1.53–1.72)</td>
<td>26 (1.84–4.14)</td>
<td>1.74 (1.15–2.51)</td>
</tr>
</tbody>
</table>

Focused Project

Morbidity and Mortality Weekly Report

Gastrochisis Trends and Ecologic Link to Opioid Prescription Rates — United States, 2006–2015

Tyrieza D. Short, MPH1;2; Erin B. Stallings, MPH1;3; Jennifer Jensen, MSPH1; Leslie A. O’Leary, PhD1; Maha M. Zaidy, PhD1; Michele K. Bohm, MPH1; Mary Erben, MPH6; Xiaoli Chen, PhD5; Tri Tran, MPH7; Deborah J. Fox, MPH8; Jane Fennoff, PhD9; Nina Forestieri, MPH10; Emily Ferrell, MPH11; Glenda M. Ramirez, MPH12; Jamie Kim, MPH13; Jing Shi, MS14; Sook Ja Cho, PhD15; Kirstan Duckett, MPH16; Norm Nelson, MS17; Katherine Zielke, MPH18; Kristen St. John, MPH19; Brennan Martin, MPH20; Carolina Clark, MD21; My-Phuong Huynh, MPH22; Colin Benusa, MPH23; Jennita Reelhuis, PhD4

Areas with high opioid prescription rates are seeing more babies born with a serious birth defect

CNN News, 17 Jan 2019

(CNN) A potentially deadly birth defect in which babies are born with exposed intestines is on the rise, and researchers are...
Data from 20 states

47% of all US births
Ongoing Projects

- Spina Bifida Lesion Level
- Time Trends Monitoring
- Turner's Syndrome
- Cause of Death
- Interpregnancy Interval

See it at the poster session!

Upcoming

- New processes for combining state data
- Data Repository
- 2020 Data Brief Topic
- State DC Meeting
  Today! 12:30 pm
Thank you!

NBDPN Data Committee