



Surveillance

Research

Prevention

AROUND THE NETWORK

2020 NBDPN Annual Meeting
March 9, 2020



National Birth Defects Prevention Network

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AROUND THE NETWORK



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

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ACHIEVEMENTS AND NEXT ADVENTURES



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



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Achievements!

BIRTH DEFECTS SURVEILLANCE SYSTEMS

Download the entire 2019 packet - PDF

Tip 1

Consejo 1

NBDPN DATA QUALITY ASSESSMENT REPORT SUMMARY 2018

Birth Defects Research

FOLIC ACID

Asegúrese de tomar 400 microgramos (mcg) de ácido fólico todos los días.

NBDPN @NBDPN · 10h
 Learn how you can participate in World Birth Defects Day: cdc.gov/ncbddd/birthde... #WorldBDDay #ManyBirthDefects1Voice @CDC_NCBDDD

Congenital Heart Disease Review: Follow the Blood

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.

Children's Healthcare of Atlanta

National Birth Defects Prevention Network (NBDPN) Surveillance, Research, & Prevention

2019 NBDPN Virtual Annual Meeting

Today's scientific sessions have been pre-recorded. To access the presentations, select presentation titles and/or slide graphics. Audio is only available via your computer sound system for the sessions below.

The CEU course name is WD4190 - (Web on Demand) 2019 National Birth Defects Prevention Network Virtual Annual Meeting. Please remember to view the [disclosure statement](#). Course detail: <https://tceols.cdc.gov/Course/Detail?activityID=6066&activityInstanceID=6929>

Meeting Welcome [Video]
 Speaker: Jason Salemi (TX)

Birth Defects from an MFM Perspective: [Video, Slides]
 Prenatal Testing and Diagnostic Techniques

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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

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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

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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....

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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

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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

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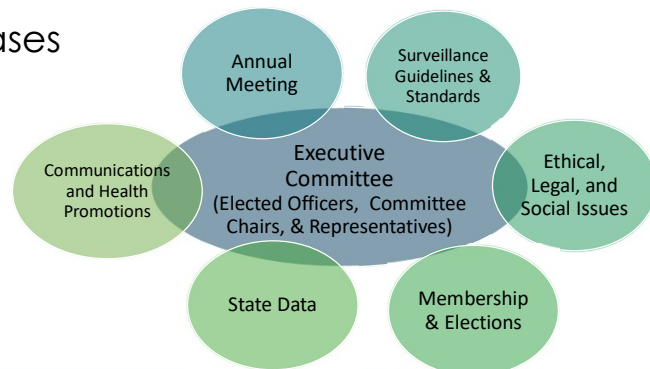
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Next Adventures for Strategic Planning

- 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



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Next Adventures for Strategic Planning



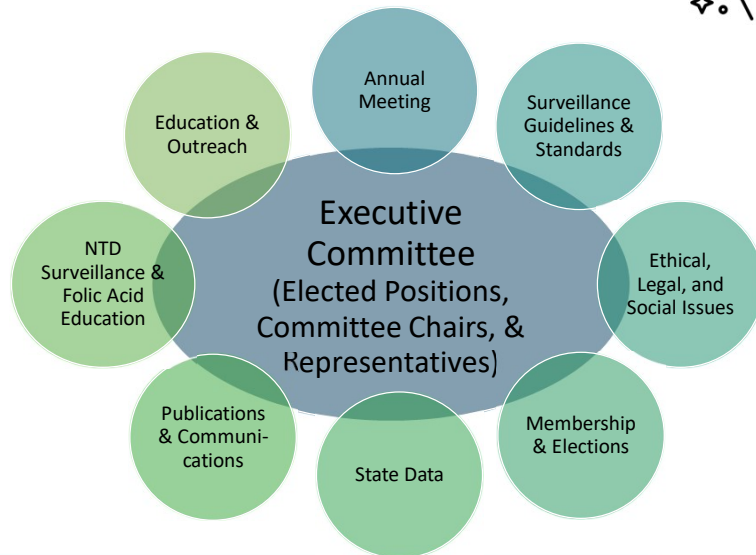
- Revision of bylaws
 - Summer 2020: out for comment and vote
- Continue reorganization into functional groups
- Establish a more traditional Board
 - Planned vote on board members in Fall 2020



Where most of the magic happens...



COMMITTEES!!





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Annual Meeting Committee

ACHIEVEMENTS



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

Chairs:

Dianna
Contreras (AZ)Russ
Kirby (FL)

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Membership & Elections Committee



ACHIEVEMENTS

- 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

Chair:
Samara Viner-
Brown (RI)

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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

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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
- Manuscript: The impact of the ICD-9-CM to ICD-10-CM transition on the prevalence of birth defects among infant hospitalizations in the United States. Birth Defects Res. 2019 Nov 1;111(18):1365-1379

ACHIEVEMENTS



Chairs:

Jason
Salemi (FL)Jean Pau
Tanner (FL)

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

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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

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State Data Committee



ACHIEVEMENTS & Next Adventures



- Will hear about shortly....



Chair:
Dominique
Heinke (MA)

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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

Chairs:



Barbara Frohnert (MN)



Lindsay Overman (AR)



Next Adventures:

- Merging of committees



Publications and Communications Committee



ACHIEVEMENTS

- 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!



709 Followers!



142 Followers!



Next Adventures:

- Merging of committees

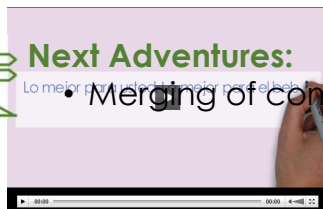
Chair:



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!



Chair:

Mary Knapp (NJ)





Birth Defects Prevention Month 2020

f 31 posts
8,440 views!

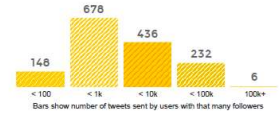
t 7 tweets
8,590 impressions!

TWEETREACH SNAPSHOT
#Best4youBest

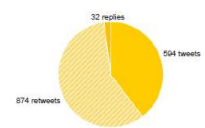
ESTIMATED REACH

3,241,627

ACCOUNTS REACHED



ACTIVITY



Bilingual twitterchat by MOD



NBDPN's Next Adventures...





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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



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NBDPN is powered by its volunteers!



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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

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THANK YOU!!



Send comments/suggestions to the Presidents
<http://bit.ly/NBDPNpresidents>

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BUSINESS UPDATE

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

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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

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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

At this time, memberships are for the individual "participating member". (2016). The official membership year runs from July 1st to June 30th of the following year. Contact nbdpninc@nbdpn.org.

- To join as a member:

In the "Members Only" section of the NBDPN web site, not only can you join as a member, but also access a multitude of resources and archived reports.

Submit your registration for membership on-line today!

Download or print the NBDPN flyer.

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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

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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

Choose 1

 Big Bird


Big Bird is a character on the children's television show Sesame Street. Officially performed by Caroll Spinney from 1969 to 2018, he is an eight-foot two-inch (249 cm) tall bright yellow anthropomorphic canary. He can roller skate, ice skate, dance, swim, sing, write poetry, draw, and even ride a unicycle. Despite this wide array of talents, he is prone to frequent misunderstandings, on one occasion even singing the alphabet as one big long word, pondering what it could mean. He lives in a large nest behind the 123 Sesame Street brownstone and right next to Oscar the Grouch's trash can and he has a teddy bear named Radar. In Season 46, Big Bird's large nest is now sitting within a small, furnished maple tree, and is no longer hidden by used construction doors. He wears a red neckerchief and straw hat on his birthday and a red and blue necktie on special occasions every year and in early television specials.

In 2000, Big Bird was named a Living Legend by the United States Library of Congress.

 Mickey Mouse


Mickey Mouse is a funny animal cartoon character and the mascot of The Walt Disney Company. He was created by Walt Disney and Ub Iwerks at the Walt Disney Studios in 1928. An anthropomorphic mouse who typically wears red shorts, large yellow shoes, and white gloves, Mickey is one of the world's most recognizable characters.

Created as a replacement for a prior Disney character, Oswald the Lucky Rabbit, Mickey first appeared in the short Plane Crazy, debuting publicly in the short film Steamboat Willie (1928), one of the first sound cartoons. He went on to appear in over 130 films, including The Band Concert (1935), Brave Little Tailor (1938), and Fantasia (1940). Mickey appeared primarily in short films, but also occasionally in feature-length films. Ten of Mickey's cartoons were nominated for the Academy Award for Best Animated Short Film, one of which, Lend a Paw, won the award in 1942. In 1978, Mickey became the first cartoon character to have a star on the Hollywood Walk of Fame.

Beginning in 1930, Mickey has also been featured extensively as a comic strip character. The Mickey Mouse comic strip, drawn primarily by Floyd Gottfredson, ran for 45 years. Mickey has also appeared in comic books such as Disney Italy's Topolino, MM - Mickey Mouse Mystery Magazine, and Wizards of Mickey, and in television series such as The Mickey Mouse Club (1955-1996) and others. He also appears in other media such as video games as well as merchandising and is a meetable character at the Disney parks.

Mickey generally appears alongside his girlfriend Minnie Mouse, his pet dog Pluto, his friends Donald Duck and Goofy, and his nemesis Pete, among others (see Mickey Mouse universe). Though originally characterized as a cheeky lovable rogue, Mickey was rebranded over time as a nice guy, usually seen as an honest and bodacious hero. In 2009, Disney began to rebrand the character again by putting less emphasis on his friendly, well-meaning persona and reintroducing the more menacing and stubborn sides of his personality, beginning with the video game Epic ...

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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) *

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Website Usage: Annual Meeting Registration

Agenda and Session Options

Sunday Training - 1:00PM-5:00PM

openings no longer available for:
Ensuring Data Quality in Birth Defects Surveillance

Monday Plenary - 8:00AM-12:00PM

- Welcome Session - 8:00AM-9:00AM;
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 standard 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.

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Website Usage: Poster Abstracts

Author Information **Poster Categories** Poster Abstract File Upload

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

Category Selection

- 1-Case Ascertainment**
Innovative approaches, use of physician office data, record linkage, prenatal 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 evaluations, 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**

National Birth Defects Prevention Network

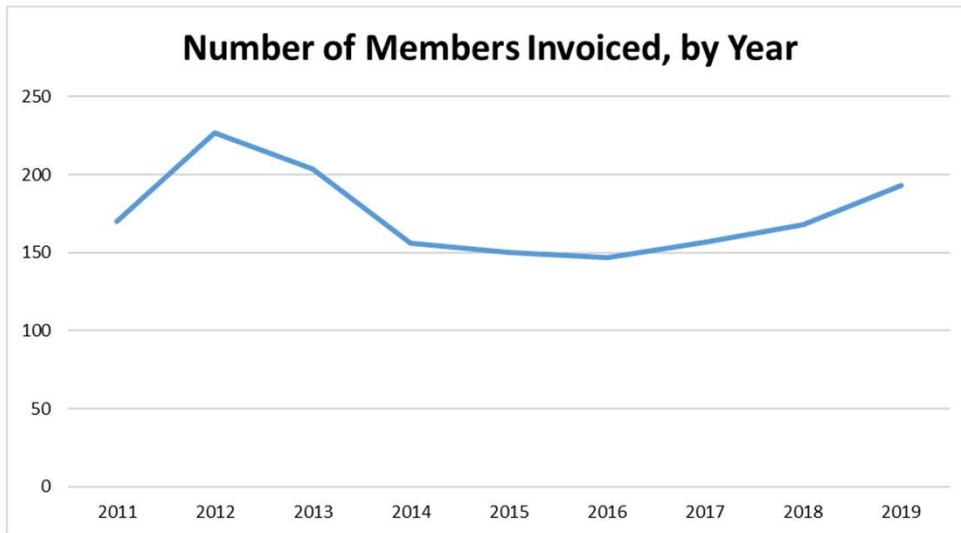
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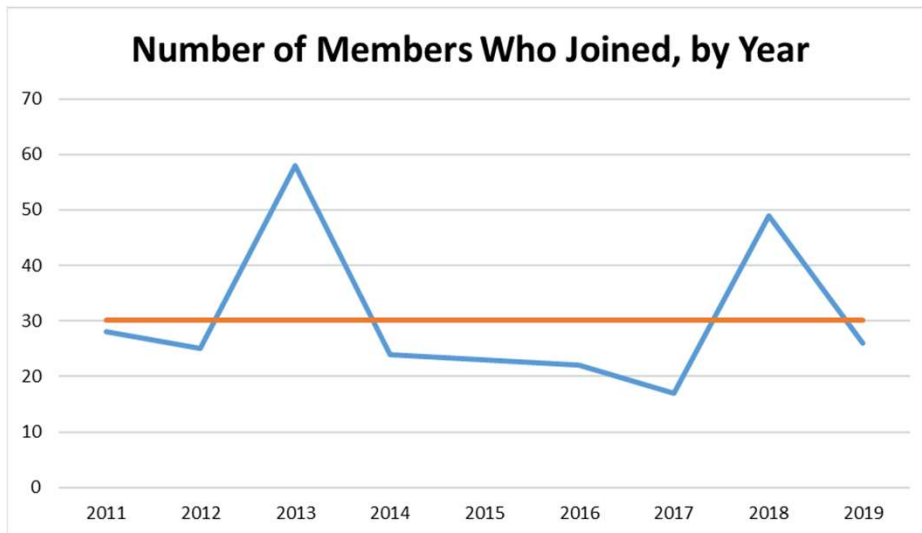
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Membership Numbers – Over Time



New Members Over Time





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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%

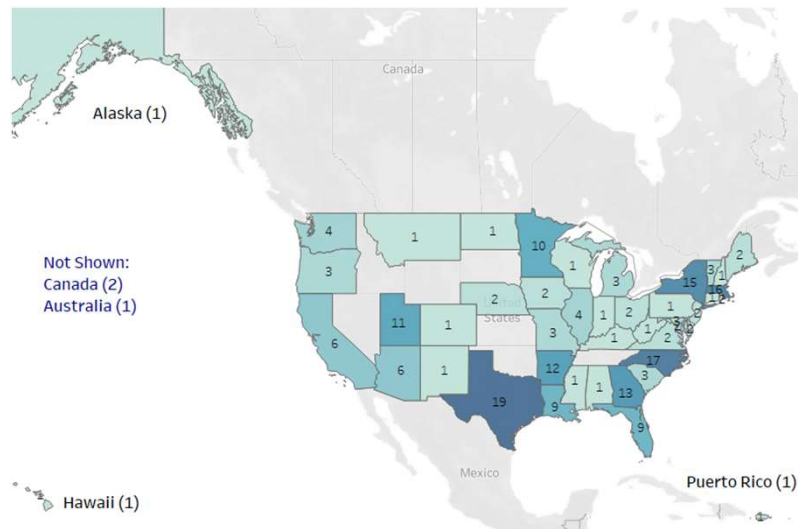
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Current Members: Geography



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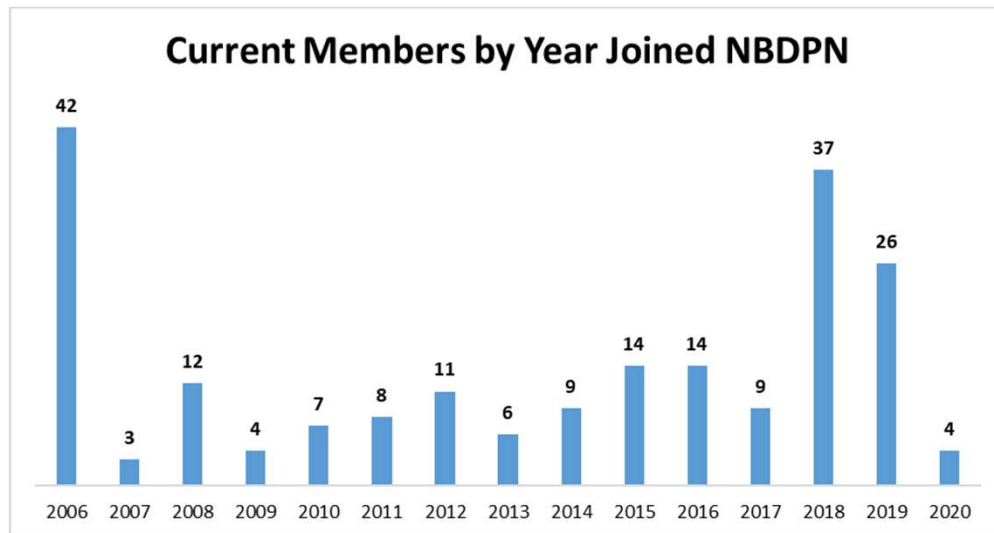


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Current Members: by Year Joined



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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

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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

Member List

[Main Menu](#)

Member Name Search

 --Any State-- ▼

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2019 Membership Survey

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

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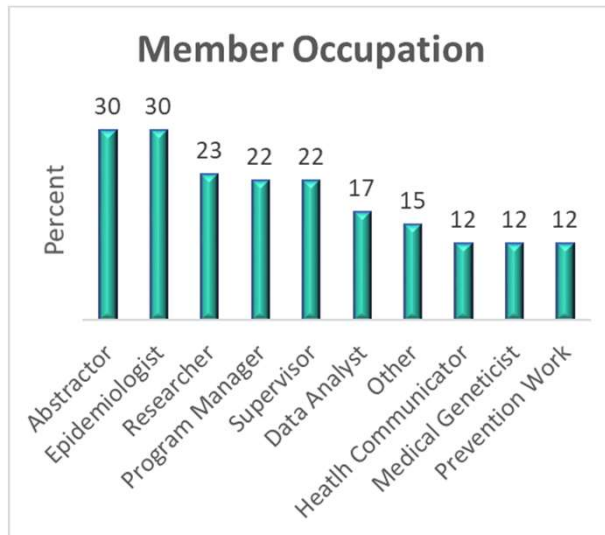
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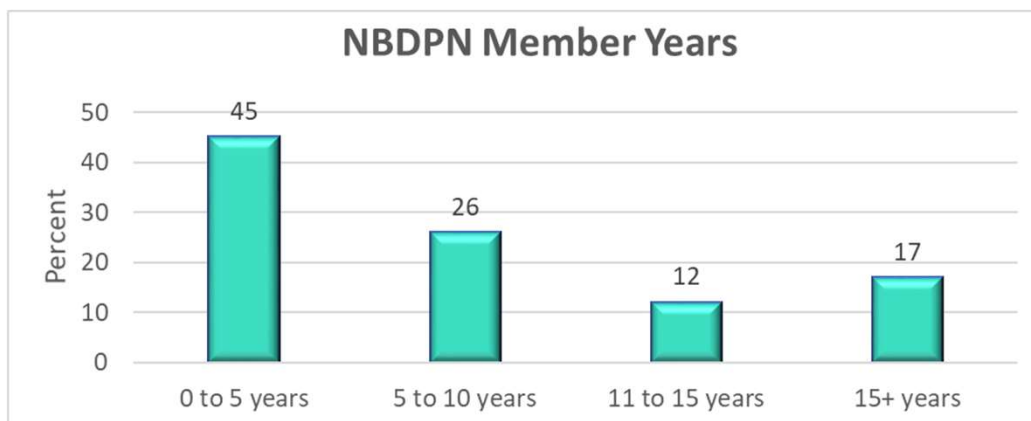


2019 Membership Survey Continued

- 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





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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%)

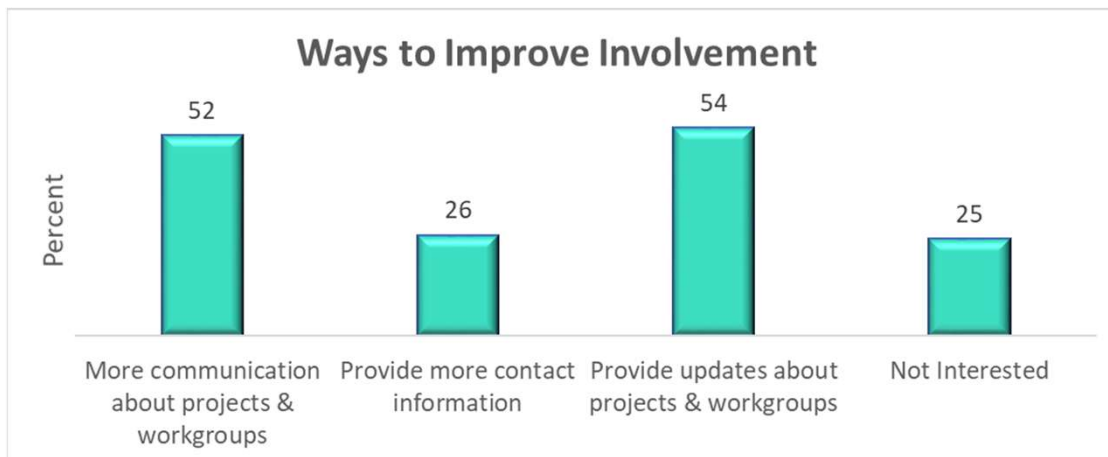
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2019 Membership Survey Continued



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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>

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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

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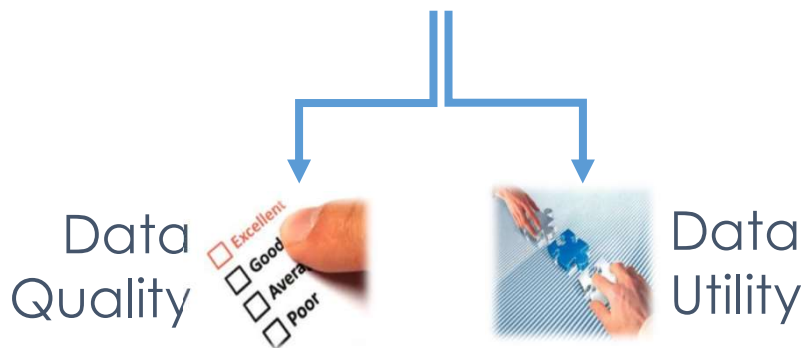


NATIONAL STANDARDS FOR BIRTH DEFECTS SURVEILLANCE

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?



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NBDPN Website Resource

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Birth Defects Surveillance Guidelines

Jump to:
Birth Defects Surveillance Guidelines
National Standards for Birth Defects Surveillance

National Standards for Birth Defects Surveillance

The National Birth Defects Prevention Network (NBDPN) is developing standards for population-based birth defects surveillance in the United States. These standards are a priority for NBDPN in order to improve the quality and consistency of birth defects data to make it more useful at the local and national levels for a variety of purposes.

National standards on data quality for birth defects surveillance are now available.

[Background](#) on the development and implementation of data quality standards for population-based birth defects surveillance
[Data Quality Assessment Tool \(2015 version\)](#)
[Overall summary results](#) from the 2019 population-based birth defects program self-assessment

The NBDPN will continue to conduct ongoing assessment of data quality performance measures and develop national standards on data utility. We welcome your input. Comments and questions can be sent to standards@nbdpn.org.

National Bi... <https://www.nbdpn.org/guidelines.php>

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

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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

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

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

DQ Summary Results Report

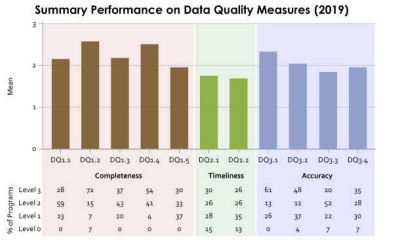
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NBDPN DATA QUALITY ASSESSMENT REPORT SUMMARY 2019

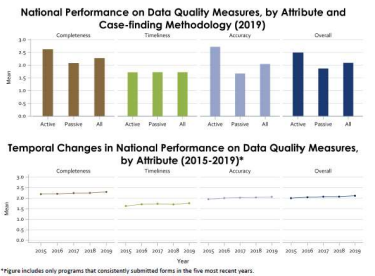
Data Quality Assessment for Population-based Birth Defects Surveillance Systems
Performance standards for birth defects surveillance are intended to improve and standardize operations, outcomes and surveillance functions across state programs, thereby making data more consistent and useful for a variety of purposes at the state, multi-state and national levels. The eleven measures reflecting data quality (DQ) were developed around completeness, timeliness and accuracy attributes (see Appendix 1). Three performance levels were associated with each measure:

- Level 1: Rudimentary level of performance by a surveillance program
- Level 2: Essential level of performance by a surveillance program
- Level 3: Optimal level of performance by a surveillance program

The expectation is that the majority of programs would be able to achieve a Level 2 on all measures.
Performance Measure Scores
The mean values for each measure's performance level, with comparative national percentages, are shown in the figure below. These results reflect the responses NBDPN received from state programs' completion of the 2019 Data Quality Self-Assessment Tool. The percent of programs by performance level is calculated for all programs in the U.S. that submitted forms in the current year, that met a level 1 for DQ1.1 and achieved an overall mean score of 1 for all measures (n=46).



NBDPN DATA QUALITY ASSESSMENT REPORT SUMMARY 2

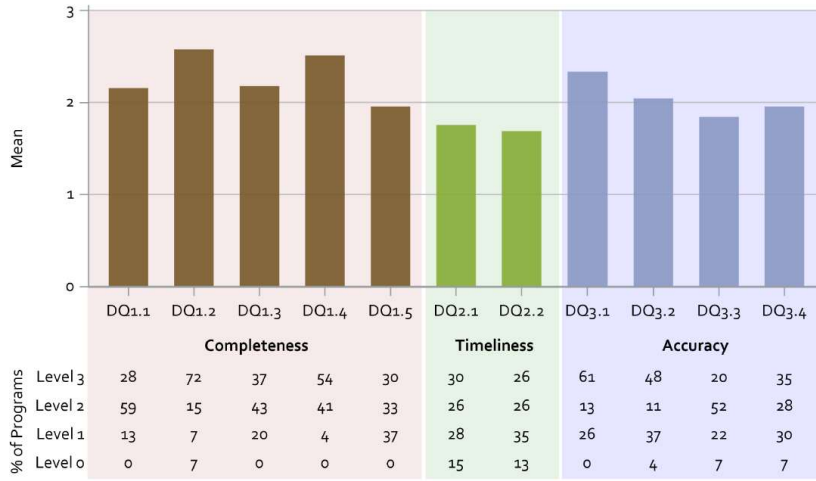


- Next Steps**
- State Programs
 - Put processes in place to ensure programs have the support necessary to achieve national standards
 - Drive as champions who raise awareness about the value of national standards for data quality
 - Identify and convey your program's need for resources to achieve national standards
 - NBDPN
 - Provide program-specific and overall summary reports
 - Assess how well the current tool measures program data quality
 - Develop Data Utility Standards
 - Incorporate Standards into the Birth Defects Surveillance Manual
 - Facilitate trainings to improve programs' ability to evaluate and enhance data quality



DQ Summary Results Report

Summary Performance on Data Quality Measures (2019)

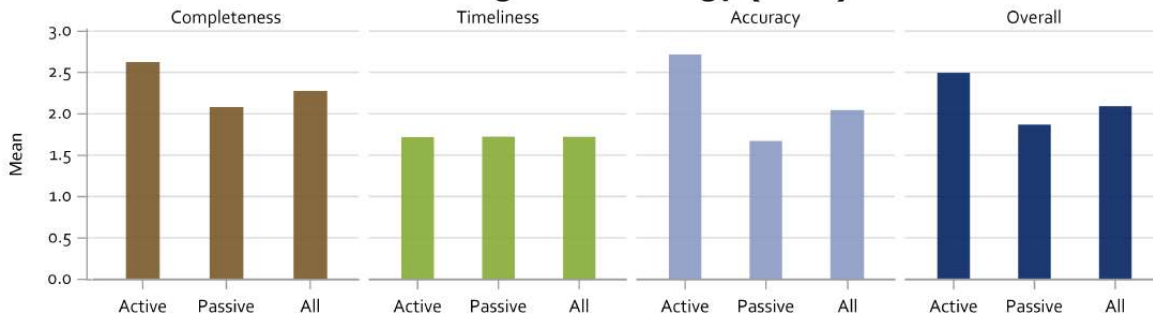


National Birth

ention

DQ Summary Results Report

National Performance on Data Quality Measures, by Attribute and Case-finding Methodology (2019)



National Birth Defects Prevention Network

Surveillance

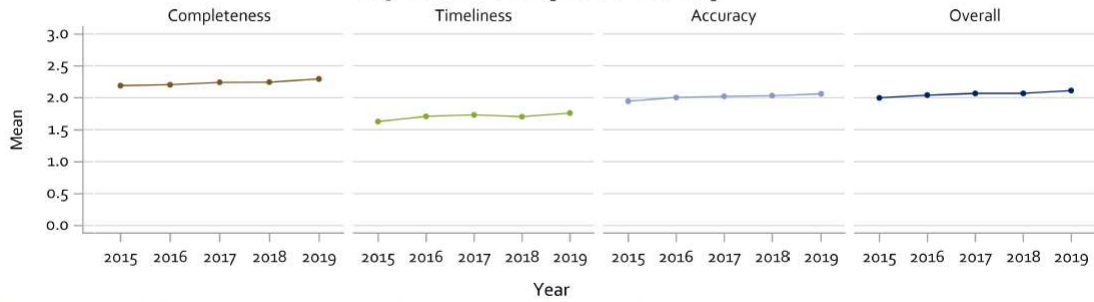
Research

Prevention



DQ Summary Results Report

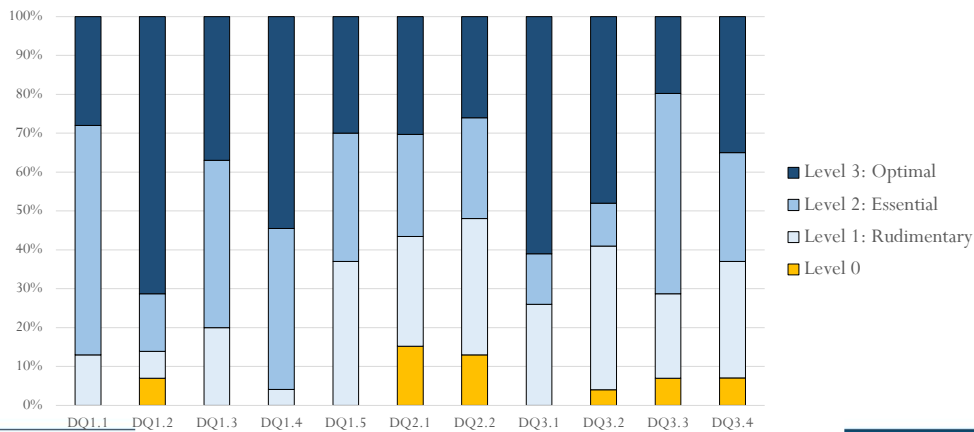
Temporal Changes in National Performance on Data Quality Measures, by Attribute (2015-2019)*



*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)





Surveillance

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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

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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

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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

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Thank you!

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MULTI-STATE DATA COLLABORATIVE PROJECTS

Dominique Heinke, ScD

She/Her/Dr

On behalf of the NBDPN Data Committee



National Birth Defects Prevention Network

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Why are multi-state
collaborations key to
NBDPN?



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NBDPN Mission



**Improve
access**
to information

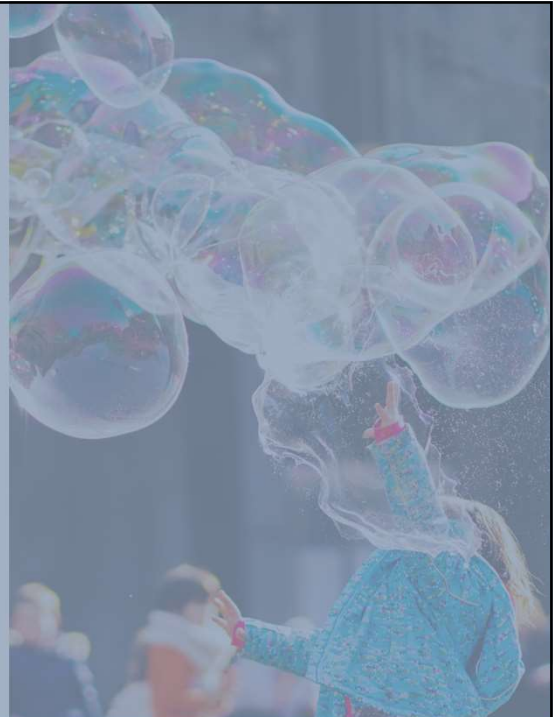


**Increase
collaboration**
within the birth
defects
community



**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



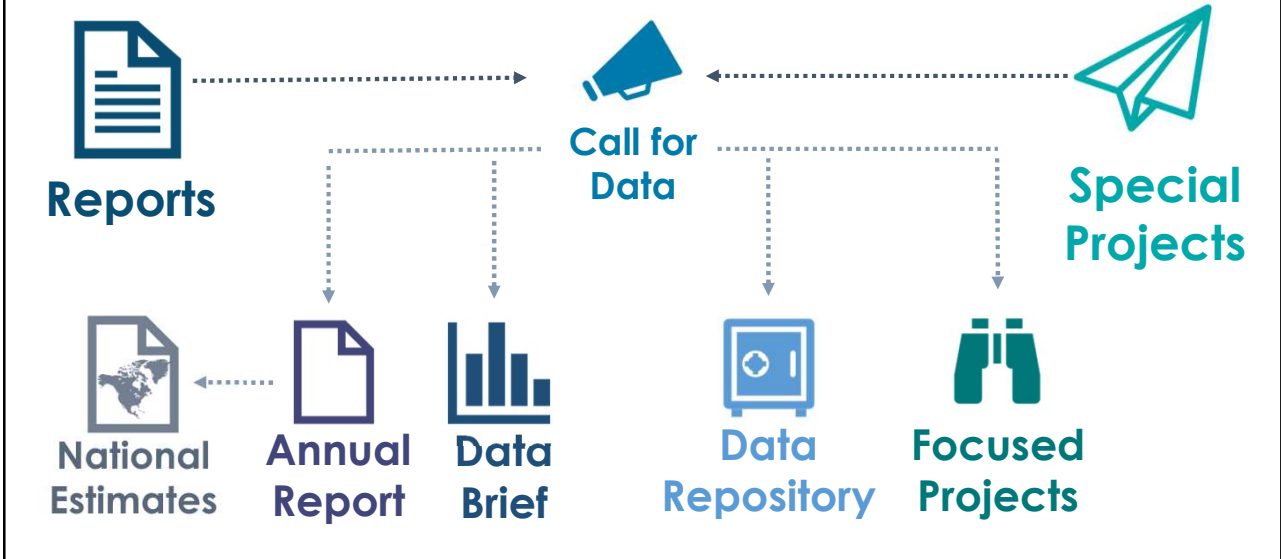
Now that's A SLICE!





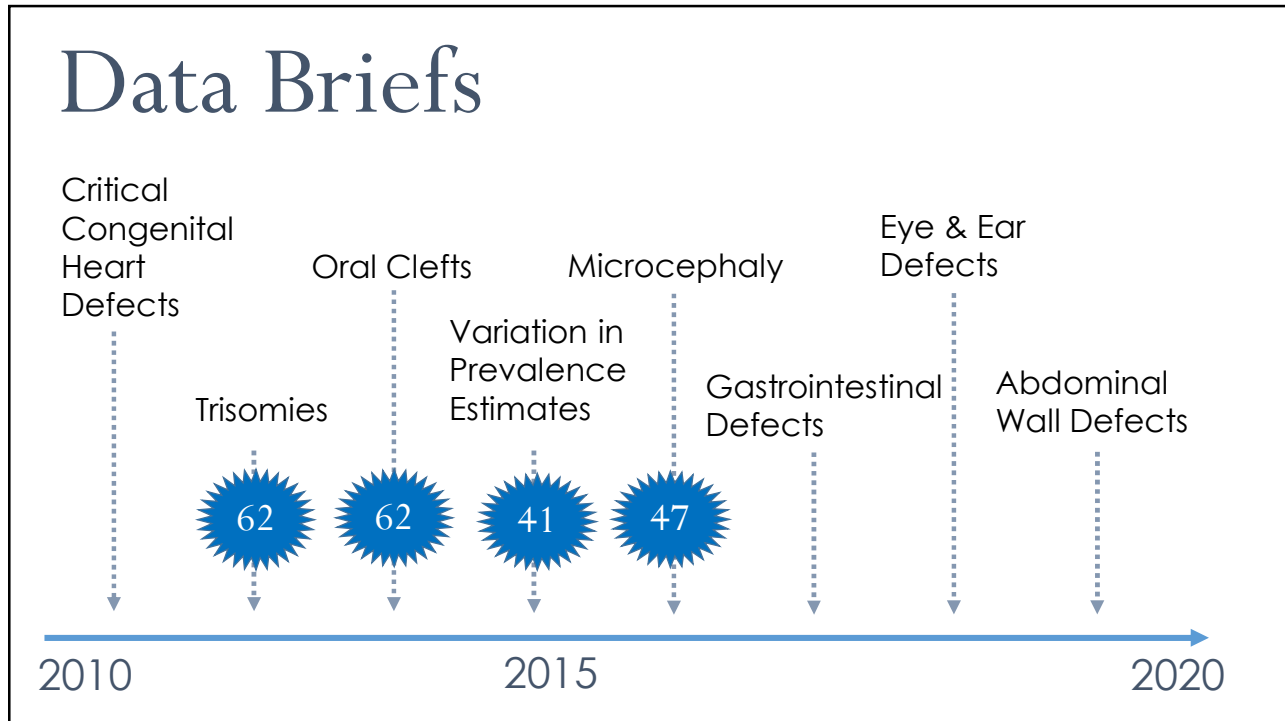
Surveillance Research Prevention

Multi-state Collaborations

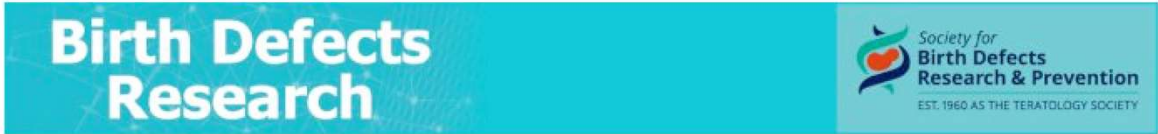




Data Briefs



2019 Data Brief



BRIEF REPORT

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](#)

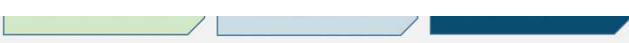




TABLE 2 Abdominal wall defect counts, prevalence, and 95% confidence intervals for 30 US population-based surveillance programs,^a 2012–2016 (prevalence per 10,000 live births)

Variable	Gastroschisis			Omphalocele		
	Count	Prevalence	95% CI ^b	Count	Prevalence	95% CI ^b
Total ^c	5,349	4.3	4.1–4.4	2,601	2.1	2.0–2.2
<i>Case ascertainment methodology^a</i>						
Active case finding	2,677	4.7	4.6–4.9	1,262	2.2	2.1–2.4
Passive case finding	2,672	3.9	3.7–4.0	1,339	1.9	1.8–2.0
<i>Maternal race/ethnicity</i>						
White, non-Hispanic	2,857	4.3	4.2–4.5	1,242	1.9	1.8–2.0
Black, non-Hispanic	632	3.2	3.0–3.5	627	3.2	2.9–3.4
Hispanic	1,524	5.0	4.8–5.3	543	1.8	1.6–1.9
Asian or Pacific Islander, non-Hispanic	105	1.6	1.3–1.9	80	1.2	1.0–1.5
American Indian or Alaska Native, non-Hispanic	71	7.2	5.6–9.1	18	1.8	1.1–2.9

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

Variable	Gastroschisis (n = 5,349 ^b)			Omphalocele (n = 2,601 ^b)		
	Count	Percent	95% CI ^c	Count	Percent	95% CI ^c
<i>Gestational age (weeks)</i>						
20–23 weeks	57	1.1	0.8–1.4	127	4.9	4.1–5.8
24–27 weeks	59	1.1	0.8–1.4	102	3.9	3.2–4.7
28–33 weeks	565	10.6	9.8–11.4	368	14.1	12.8–15.5
34–36 weeks	2,510	46.9	45.6–48.3	530	20.4	18.8–22.0
37+ weeks	2,096	39.2	37.9–40.5	1,428	54.9	53.0–56.8
<i>Birth weight (grams)</i>						
Very low birth weight (less than 1,500 g)	291	5.4	4.8–6.1	370	14.2	12.9–15.6
Low birth weight (1,500–2,499 g)	2,785	52.1	50.7–53.4	629	24.2	22.5–25.9
Normal birth weight (≥2,500 g)	2,170	40.6	39.2–41.9	1,426	54.8	52.9–56.8
<i>Plurality</i>						
Singleton	5,146	96.2	95.7–96.7	2,400	92.3	91.2–93.3
Twin or multiple	117	2.2	1.8–2.6	157	6.0	5.2–7.0
<i>Pregnancy outcome^e</i>						
Live births	3,181	94.3	93.4–95.0	1,237	80.7	78.7–82.7
Non-live births	190	5.6	4.9–6.5	293	19.1	17.2–21.2



TABLE 4 Co-occurring birth defects by organ system for abdominal wall defects from 15 US population-based active case-finding surveillance programs,^a 2012–2016

ICD ^c code groups	Gastroschisis (<i>n</i> = 2,677 ^b)			Omphalocele (<i>n</i> = 1,262 ^b)		
	Count	Percent	95% CI ^d	Count	Percent	95% CI ^d
Congenital anomalies (740–759)/congenital malformations, deformations and chromosomal abnormalities (Q00-Q99) ^c	898	33.6	31.8–35.4	904	71.8	69.2–74.3

National Estimates

National Estimates and Race/Ethnic-Specific Variation of Selected Birth Defects in the United States, 1999–2001

Mark A. Canfield,^{1*} Margaret A. Honein,² Nataliya Yuskiv, Jian Xing,^{2,3} Cara T. Mai,² Julianne S. Collins,⁴ Owen Devine,⁵ Joann Petrini,¹ Tumu A. Ramadhani,¹ Charlotte A. Hobbs,² and Russell S. Kirby⁶ for the National Birth Defects Prevention Network

National population-based estimates for major birth defects, 2010–2014

Cara T. Mai¹ | Jennifer L. Isenburg¹ | Mark A. Canfield² | Robert E. Meyer^{3,4} | Adolfo Correa⁵ | Clinton J. Alverson¹ | Philip J. Lupo⁶ | Tiffany Riehle-Colarusso¹ | Sook Ja Cho⁷ | Deepa Aggarwal⁸ | Russell S. Kirby⁹ | National Birth Defects Prevention Network

Updated National Birth Prevalence Estimates for Selected Birth Defects in the United States, 2004–2006

Samantha E. Parker,^{1,2} Cara T. Mai,^{1*} Mark A. Canfield,² Russel Rickard,⁴ Ying Wang,⁵ Robert E. Meyer,⁷ Patrick Anderson,⁸ Craig A. Mason,⁹ Julianne S. Collins,⁷ Russell S. Kirby,¹⁰ and Adolfo Correa¹ for the National Birth Defects Prevention Network

Cited over **1300** times!





Published Multi-state

Multi-state Collaborative Projects

The National Birth Defects Prevention Network helps facilitate collaborative projects. Abstracts of publications from the Network's numerous collaborative projects are available on the website and should be directed to the state data committee.

Prevalence of selected birth defects by maternal nativity status, United States, 1999-2007. Copeland GE, Flood TJ, Isenburg J, Canfield MA, National Birth Defects Prevention Network. Birth Defects Research Part A. 2016 Apr;102(4):284-293. (State Data Committee)

Population based birth defects data in the United States, 2011-2015: A focus on selected birth defects. Copeland GE, Flood TJ, Isenburg J, Kirby RS, Short TD, Nembhard WN, Wang Y, Harpavat S, Harpavat S. Birth Defects Research Part A. 2017 Nov 15;110(11):1478-86.

Birth Defect Survival for Hispanic Subgroups. Lopez KN, Nembhard WN, Wang Y, Canfield M. Birth Defects Research Part A. 2017 Nov 15;110(11):1478-86.

Population based birth defects data in the United States, 2010-2014: A focus on selected birth defects. Copeland GE, Flood TJ, Isenburg J, Kirby RS, Short TD, Nembhard WN, Wang Y, Harpavat S, Harpavat S. Birth Defects Research Part A. 2017 Nov 15;110(11):1478-86.

Prevalence trends of selected major birth defects: A multi-state population-based study. St Louis AM, Kim K, Browne ML, Liu G, Liberman RF, Nembhard WN, Canfield MA, Isenburg J, Flood TJ, Harpavat S, Harpavat S. Birth Defects Research Part A. 2017 Nov 15;110(11):1478-86.

Maternal exposure to ozone and PM2.5 and the prevalence of orofacial clefts. Flanders WD, Liu Y, Shin M, Canfield MA, Kirby RS. Environmental Health Perspectives. 2017 Nov 15;110(11):1478-86.

Using state and provincial surveillance programs to reduce risk of recurrence of selected birth defects: A missed opportunity? Flood TJ, Rienks CM, Flores AL, Mai CT, Frohner Research Part A: Clinical and Molecular Teratology. 2016 Nov 1;106(11):875-80.



Population based birth defects data in the United States, 1995-2005. Marshall J, Salemi J, Tanner JP, Meyer RE, Druschel CM, Rickard R, Kirby RS, for the National Birth Defects Prevention Network. Birth Defects Research Part A. 2016 Apr;102(4):284-293. (State Data Committee)

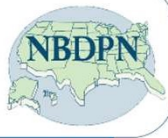
Population based birth defects data in the United States, 1995-2005. Marshall J, Salemi J, Tanner JP, Meyer RE, Druschel CM, Rickard R, Kirby RS, for the National Birth Defects Prevention Network. Birth Defects Research Part A. 2016 Apr;102(4):284-293. (State Data Committee)

Population based birth defects data in the United States, 1995-2005. Marshall J, Salemi J, Tanner JP, Meyer RE, Druschel CM, Rickard R, Kirby RS, for the National Birth Defects Prevention Network. Birth Defects Research Part A. 2016 Apr;102(4):284-293. (State Data Committee)

Population based birth defects data in the United States, 2007 to 2011: highlighting selected birth defects. Isenburg J, Canfield MA, Rickard R, Olney RS, Stallings EB, Beck M, Hashmi SS, Cho SJ, Wang Y, Harpavat S, Harpavat S. Birth Defects Research Part A. 2014;100(11):895-904.

Population based birth defects data in the United States, 1999-2007. Canfield MA, Mai CT, Wang Y, Rutkowski R, Fornoff J, Irwin N, Copeland G, Flood TJ, Meyer RE, Rickard R, Alverson Prevention Network. Am J Public Health 2014;104(9):e14-23.

Population based birth defects surveillance programs in the United States, 2006 to 2010: Featuring selected birth defects. Feldkamp ML, Marengo LK, Bugenske EM, Thorpe PG, Jackson JM, Correa A, Rickard R, Canfield MA, National Birth Defects Prevention Network. Birth Defects Res A Clin Mol Teratol. 2013 Nov;97(11):709-25.



Surveillance

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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 Suhl, 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 Isenburg, 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

Defect	Non-Hispanic White ^a (referent)		Non-Hispanic American Indian/Alaska Native ^a				Any American Indian/Alaska Native, regardless of Hispanic ethnicity ^a			
	Cases	Prevalence ^b (95% CI)	Cases	Prevalence ^b (95% CI)	cPR (95% CI)	aPR ^c (95% CI)	Cases	Prevalence ^b (95% CI)	cPR (95% CI)	aPR ^c (95% CI)
Encephalocele	444	0.62 (0.56–0.67)	13	1.41 (0.75–2.41)	2.29 (1.25–3.80)	1.78 (0.36–5.30)	14	1.34 (0.73–2.25)	2.17 (1.22–3.55)	1.74 (0.40–4.89)
Anotia/microtia	843	1.17 (1.09–1.25)	43	4.67 (3.38–6.29)	3.99 (2.89–5.34)	2.72 (1.55–4.45)	49	4.7 (3.47–6.21)	4.01 (2.97–5.28)	2.75 (1.62–4.36)
Cleft lip +/- cleft palate	6,955	9.67 (9.44–9.89)	185	20.09 (17.19–22.98)	2.08 (1.79–2.40)	1.69 (1.41–2.01)	203	19.46 (16.78–22.13)	2.01 (1.75–2.31)	1.65 (1.39–1.95)
Cleft palate alone ^d	4,573	6.36 (6.17–6.54)	60	6.52 (4.97–8.39)	1.03 (0.79–1.31)	N/A	65	6.23 (4.81–7.94)	0.98 (0.76–1.24)	N/A
Gastroschisis ^e	1967	3.1 (2.96–3.24)	59	6.85 (5.22–8.84)	2.21 (1.69–2.83)	1.12 (0.76–1.57)	64	6.52 (5.02–8.33)	2.10 (1.62–2.67)	1.07 (0.74–1.49)
Upper limb reductions	1985	2.76 (2.64–2.88)	40	4.34 (3.10–5.91)	1.57 (1.13–2.12)	1.15 (0.75–1.67)	43	4.12 (2.98–5.55)	1.49 (1.09–1.99)	1.06 (0.70–1.53)
Lower limb reductions	1,079	1.5 (1.41–1.59)	24	2.61 (1.67–3.88)	1.74 (1.13–2.54)	1.37 (0.81–2.18)	26	2.49 (1.63–3.65)	1.66 (1.10–2.40)	1.36 (0.82–2.11)
Trisomy 18	1,168	1.62 (1.53–1.72)	26	2.82 (1.84–4.14)	1.74 (1.15–2.51)	1.52 (0.97–2.27)	28	2.68 (1.78–3.88)	1.65 (1.11–2.35)	1.52 (0.99–2.23)

Focused Project

Morbidity and Mortality Weekly Report

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

Tyiesha D. Short, MPH^{1,2}; Erin B. Stallings, MPH^{1,3}; Jennifer Isenburg, MSPH¹; Leslie A. O’Leary, PhD¹; Mahsa M. Yazdy, PhD⁴; Michele K. Bohm, MPH⁵; Mary Ethen, MPH⁶; Xiaoli Chen, PhD⁴; Tri Tran, MPH⁷; Deborah J. Fox, MPH⁸; Jane Fornoff, 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 Reefhuis, PhD¹



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...



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Data from 20 states

47% of all US births

FIGURE 1. Trends in gastroschisis prevalence, by maternal age group — 20 states, 2006–2015*

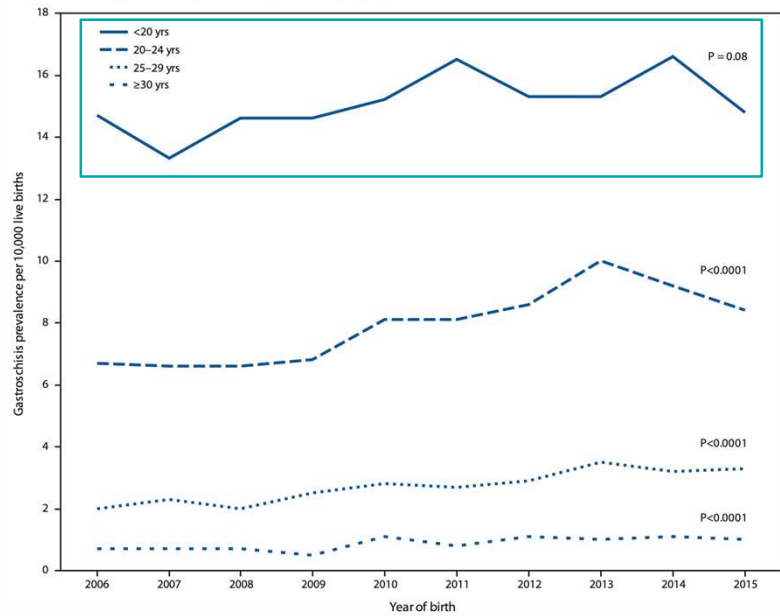
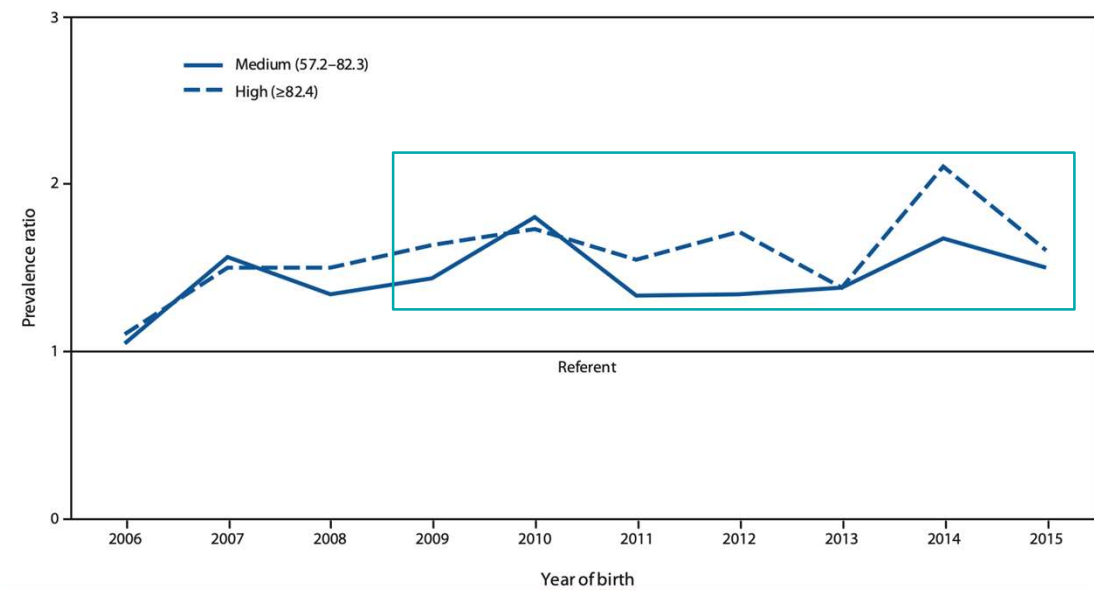


FIGURE 2. Trends in gastroschisis prevalence ratio, by year* and annual opioid prescription rate category† — 20 U.S. states, 2006–2015[§]





Surveillance

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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





Surveillance Research Prevention

Thank
you!



NBDPN Data Committee

National Birth Defects Prevention Network

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