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BIRTH DEFECTS TRACKING AND PREVENTION ONE YEAR LATER:

One Step Forward. Two Steps Back?

As part of its ongoing efforts to strengthen the fundamentals of our public health defenses, Trust for America's Health (TFAH) has identified nationwide tracking of chronic conditions and diseases as a priority. Monitoring and tracking initiatives, like registries created to monitor birth defects, form the backbone of a vital, functional and responsive public health network.

- **Birth Defects Registries: A Key to Prevention**

State monitoring programs and registries provide state policy makers, health care providers, and researchers with basic information about rates of birth defects in order to help identify trends and improve access to services for families of affected children. When combined with studies of genetics, molecular biology, etiologic investigations and environmental exposures, the information provided by birth defects registries has the potential to help uncover the causes of these conditions, thus reducing infant morbidity and mortality, and preventing future cases. Sadly, nearly one million births each year — as many as 25 percent — are not covered in birth defects monitoring programs.

- **Progress is Being Made, but is Threatened by State Budget Pressures**

Increasingly, states are recognizing the effectiveness and value of birth defects registries. Since the release of TFAH's 2002

report, *"Birth Defects Tracking and Prevention: Too Many States are Not Making the Grade,"* over 80 percent of states have taken specific steps to improve their birth defect registries and/or monitoring programs.

At the same time, March of Dimes chapters around the country have been strong and active advocates at the state level for establishing and expanding these programs, educating policy makers and elected officials about their importance and role in preventing birth defects.

While much more remains to be done, the progress that has been achieved over the last year is now threatened by state budget deficits. Given the magnitude of budget deficits in nearly every state, it is very possible that even those states that met TFAH's minimum standard for funding birth defects registries in 2002 — at least ten percent of the registry must be state funded — will miss the mark in 2004. Meeting the "good" or "better" standard — at least 25 percent must be state funded — is even more unlikely.

Birth Defects Registries: Assessing Progress

BIRTH DEFECTS ARE THE LEADING CAUSE OF DEATH AMONG INFANTS

Birth defects are the leading cause of death among infants in the United States, accounting for approximately 20 percent of all infant deaths annually. While some birth defects can be surgically treated, a child affected by a birth defect may often require frequent and painful medical care.

Beyond the direct emotional and health impacts on affected children and their families, medical treatment and support services are a tremendous financial burden. Recent estimates place the annual costs of birth defects in the United States at approximately \$8 billion. The lifetime costs estimated for each affected child range from \$140,000 to \$700,000, depending on the type of birth defect.

To make real progress in preventing birth defects, the United States needs to do a first-class job of tracking birth defects state-by-state. State-by-state tracking of birth defects is usually carried out by state health departments, which apply public health science to establish monitoring programs that look for birth defects cases in the state and follow them, while protecting privacy, through a centralized registry or database. With top-notch scientific information about birth defects, public health practitioners can answer questions more rapidly about risk factors in a particular community and more readily study the causes of birth defects and how to prevent them.

Registries provide public health scientists with basic information about the types of birth defects that are occurring, in what areas, and whether there is a trend. The information can be used to better target resources, provide services to affected families and study the causes of birth defects and the risk factors involved. Registries can also help to determine whether public policy changes have led to a reduction in birth defects. Finally, these registries are essential to a vibrant, effective public health network in the United States.

This report updates the 2002 TFAH report, entitled “Birth Defects Tracking and Prevention: Too Many States are Not Making the Grade.” Among that report’s key findings:

- Despite the effectiveness and value of birth defects registries, too many states do not have adequate programs. In 2000, more than 600,000 births were not covered by an operational registry and almost 300,000 births occurred in states with no registries at all.
- Based on a number of criteria, including ability to carry out tracking, data use, prevention and research capacity, data sharing capacity and resources devoted to the task, states were given a grade from A-F. Only eight programs in the 50 states, the District of Columbia and the Commonwealth of Puerto Rico earned an A. Even among these registries, certain minimum standards were not always met.
- The majority of states did not make the grade. Nine states have no program at all, or a program so marginal that it received an F. Fourteen programs earned a B and ten received a C. Another 11 received a D, indicating that they are only beginning to develop programs.
- Two-thirds of states with registries do not explore any possible links between birth defects and environmental exposure information, or other state registries such as cancer registries. That means that opportunities to learn about potential causes and prevention of birth defects are being lost.
- State health officials want to build capacity for birth defects surveillance, but they lack the necessary resources to do so.

DESPITE REDUCED INFANT MORTALITY, BIRTH DEFECTS PERSIST

Infant mortality in the United States has fallen dramatically in the last several decades. Yet, during this same period, the proportion of infant deaths due to birth defects has increased. Unfortunately, the causes of between 65-80 percent of all birth defects and related conditions are still unknown, which complicates prevention efforts.

Based on these findings, TFAH issued the following series of recommendations aimed at preventing future birth defects and enhancing or establishing state birth defect registries.

National Action Step

■ The United States should establish a nationwide health tracking network built on current and planned state efforts that provide researchers, policy makers and communities data about chronic diseases, including birth defects, and about environmental factors that might be linked to them. This system should protect confidentiality and encourage chronic disease prevention, not just identification and treatment. Birth defects monitoring programs should be a vital part of this nationwide health tracking network.

CDC Action Steps

■ By 2003, CDC should finalize standards for birth defects registries and Monitoring programs. The minimum standards outlined in this report provide CDC with a place to start. The new CDC Center on Birth Defects and Developmental Disabilities should provide leadership in ensuring that states reach or exceed minimum standards. The Center should also ensure that data from different states can be compared.

■ By 2004, CDC should collaborate with the National Institute of Environmental Health Sciences, the Environmental Protection Agency, or other federal agencies to fund up to ten state pilot studies that examine the links between the environment and birth defects.

■ By 2004, CDC should fund birth defects programs in every state.

State Action Steps

■ By 2004, every state should meet or exceed minimum registry standards established by CDC. States that currently do not meet the minimum standards should develop a plan at once to achieve them. States that are at or above minimum standards should develop a plan to ensure and maintain quality programs.

■ By 2004, every state should identify or create sources of data about environmental exposures. Birth defects monitoring programs should use these data to explore the connections between environmental exposures and birth defects.

■ By 2004, every state legislature should provide 25 percent of the funding for its birth defects monitoring program. This commitment is necessary to ensure that states can maintain sustainable programs in collaboration with CDC.

Overall, incremental progress has been made since TFAH issued its 2002 birth defects tracking and prevention report. Based on updated information provided by most states, 43 of the 52 jurisdictions graded (50 states, the District of Columbia and Puerto Rico), have taken concrete steps to

establish a birth defects registry or augment an existing one.

While much more remains to be done, this progress is encouraging. Yet, even these moderate improvements are at risk due to rising budget deficits at every level of government.

STATE	2002 GRADE	CHANGES IN REGISTRY PROGRAM	STATUS
Kentucky	B	Change in law now allows voluntary collection of data from outpatient clinics; awarded CDC Birth Defects grant in 2002	↑
Louisiana	D	Data collection beginning; advisory board formed; staff hired	↑
Maine	D	Collecting initial data; awarded CDC Birth Defects grant in 2002	↑
Maryland	C	Birth defects data updated	↑
Massachusetts	A	CDC birth defects grant renewed for an additional five years	↑
Michigan	C	Birth defects data updated; hired new staff; legislative change to allow data collection on fetal deaths; awarded HRSA and CDC Birth Defects grant in 2002	↑
Minnesota	D	Awarded CDC Birth Defects grant in 2002	↑
Mississippi	D	Completing initial report	↑
Missouri	B	Collecting fetal death data; awarded CDC Birth Defects grant in 2002	↑
Montana	D	Registry receives direct reporting from doctors; staff reviews genetic records for potential cases; tracking 7 categories of birth defects and 34 conditions; awarded CDC Birth Defects grant in 2002	↑
Nebraska	B	Birth defects data updated	↑
Nevada	C	Added data from northern Nevada; legislation introduced in state Senate to provide funding for the registry; moving to a passive system	—
New Hampshire	D	Awarded CDC Birth Defects grant in 2002	↑
New Jersey	B	Loss of CDC funding; ability to conduct research diminished	↓
New Mexico	B	Awarded CDC Birth Defects grant in 2002	↑
New York	B	Birth defects data updated but loss of CDC funding is significant; research capacity diminished	↓
North Carolina	C	Increase surveillance and research staff; received CDC Birth Defects grant in 2002	↑
North Dakota	F	Expect to have a limited registry by 6/2003	↑
Ohio	F	No changes known	—
Oklahoma	A	Expand program to explore potential links between neural tube defects and Superfund sites; data available through 1998; awarded CDC Birth Defects grant in 2002	↑
Oregon	F	Linking newborn with genetic screening	↑
Pennsylvania	D	Developing pilot program and protocols for linkage to services; expected to cover entire state by 2004	↑
Puerto Rico	C	Adding additional conditions to registry	↑
Rhode Island	D	Legislation introduced in state House and Senate to require a birth defects registry; hearings held in state House	↑
South Carolina	B	Awarded CDC Birth Defects grant in 2002	↑
South Dakota	F	No changes known	—
Tennessee	C	Birth defects data updated; pilot program will expand state-wide in 2003; creating linkages with genetic and newborn screening data	↑
Texas	A	Availability of statewide birth defects data updated; change in case definition to include deliveries under 20 weeks	↑
Utah	C	Awarded CDC Birth Defects grant in 2002	↑
Vermont	F	Creating a legislative report with a commission including outside experts on shape/scope of registry	↑
Virginia	B	Move to web based system for better data collection from hospitals; awarded CDC Birth Defects grant in 2002	↑
Washington	D	Facilities reporting to state almost doubled; electronic reporting system is planned	↑
West Virginia	C	Moving from passive to active system; hiring additional staff; legislation passed to establish an advisory board; awarded CDC Birth Defects grant in 2002	↑
Wisconsin	D	No changes known	—
Wyoming	F	No changes known	—

Progress Threatened: Budget Pressures

In 2002, working with the National Birth Defects Prevention Network (NBDPN), one of the criteria established by TFAH in its grading of birth defects registries related to the state's funding commitment. The minimum standard required that a state provide at least ten percent of the funding and that additional funds come from at least one other source, e.g., CDC. To meet the "good" or "better" standard, the state needed to provide at least 25 percent of the funding for the birth defects registry. Given the magnitude of deficits at every level of government, it is unlikely that even those few states that met those standards in 2002 will be able to do so in 2004.

According to the National Conference of State Legislatures (NCSL), the vast majority of states are experiencing significant budget shortfalls. Midway through fiscal year 2003, which for most states ends on June 30, 2003, 36 states were projecting a combined budget gap of \$25.7 billion. The prospects for FY 2004 are even bleaker. Meeting in Washington, D.C. in February 2003, the nation's governors projected a collective budget shortfall of \$82 billion in the coming fiscal year.

Since most states are forbidden constitutionally to run deficits, and in these days when tax increases are believed by some legislators to mean political suicide at the ballot box, the majority freeze or cut government services to balance the books. For years, public health programs have been on the front line for budget cuts. Historically, public health line items are the first victims of the budget ax, often receiving a disproportionate share of the overall cuts.

State birth defects registries are no exception.

■ For example, the state of Texas has considered the option of "zeroing out" the general revenue funding for its birth

defects registry. As one of just eight states to earn an "A" for its birth defects prevention program in 2002, the state is widely acknowledged as a model birth defects monitoring program. In Texas, state funding represents about 55 percent of the overall birth defects registry program. State officials predict a cut of the magnitude proposed as a deficit reduction measure will decimate the program or cause its total elimination. The Texas chapter of the March of Dimes and other advocacy organizations are asking the State Legislature to restore funding for its birth defects registry.

■ Oklahoma, another state receiving an "A" in 2002, has undergone a series of budget cuts since the TFAH report was released. The state met the "good" criteria of providing at least 25 percent of the funds for the registry. Cuts in FY 03 are 7.85 percent. At the present time, costs for the registry have been shifted to other funds in order to maintain current programmatic activities. It is highly unlikely that the Oklahoma registry program will receive the "good" rating next year; in fact, its "A" grade is in jeopardy.

■ Colorado, a “B” state, received a CDC birth defects registry grant following the 2002 TFAH report. Ironically, significant state budget cuts will cause state officials to reduce core birth defects surveillance funds. Given the circumstances, it is very possible that the CDC funds will be used to restore core activities rather than support enhancements that might earn the state an “A.” Again, Colorado met the 25 percent state funding criteria in 2002 and will likely miss the mark when TFAH issues its 2004 report.

While these examples are anecdotal, they reflect trends across the 52 programs graded by TFAH in 2002. Across-the board budget cuts, hiring freezes, layoffs or furloughs have been implemented in almost every state. Since public health often bears more than a proportional share of these budget cuts, there is little doubt that these approaches to budget shortfalls have a negative, and in some cases fatal, impact on state birth defects registry programs.

At the federal level, CDC is committed to helping state birth defects surveillance programs, but the amount of the Center’s funds

available to states is limited, so CDC will not be able to make up the shortfall. CDC does anticipate that some program activities will be impacted and the quality and timeliness of data collection will suffer. It is also possible that some CDC research activities will be affected by changing surveillance methods due to budget cuts at the state level.

By slashing public health programs like birth defects monitoring, the states are missing an opportunity to realize serious long-term budget savings. In addition to their value in preventing birth defects and improving the health of children, funding robust birth defects monitoring programs could actually save states money over time. The cost of prevention programs are a fraction of the cost of treating chronic diseases and conditions.

Given that the Medicaid budgets are among the fastest growing expense lines in every state budget, investing in public health programs like the birth defects registries not only shores up the nation’s ability to respond to current and emerging health threats, it also makes good long-term economic sense.

Conclusions

■ Of the 52 jurisdictions graded by TFAH in 2002, all but nine have taken incremental steps to improve their birth defect registries. More than eighty percent of jurisdictions are moving in the right direction. Yet, even this limited progress is threatened by state budget cuts.

■ In 2002, 33 states had yet to meet TFAH’s suggested minimum state funding level of ten percent of costs of the

birth defects registry. Due to widespread and nearly universal budget deficits besieging state governments, it is likely that the number of states missing the mark in 2004 will increase significantly.

■ Cuts to state birth defects registries further weaken public health defenses in the United States and represent a lost opportunity when it comes to reducing the costs of expensive treatment and care.

As part of its commitment to issuing a report examining birth defects monitoring programs every two years to chart progress in this important area, TFAH will issue a full-scale report in 2004 that documents additional progress, highlights data gaps, and identifies additional recommendations for improvement.

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