

## POLICY CHANGE IN REPORTING BIRTH DEFECTS TO IMPROVE SURVEILLANCE EFFORTS

## THE PROBLEM

About 1 in 33 babies are born with a birth defect. In spite of much research, we still don't always know why a birth defect occurs. Accurate birth defect surveillance is necessary for researchers and public health professionals to assess factors that influence birth defects—from environmental factors to vectorborne infections like Zika. Wisconsin's birth defects registry has been in place since 2004. Historically, that registry was an "opt-in", or passive, registry; parents had to provide consent for their child to be included in the registry. Like other "opt-in" systems, Wisconsin's registry underperformed with respect to data completeness. Inadequate surveillance had direct consequences by limiting the availability of data for research and public health response. Emerging conditions, such as Zika, made it clear that improved birth defect surveillance was a public health necessity.

## WHAT WE DID

In 2015, the Wisconsin Tracking Program was invited to speak to the Wisconsin Council on Birth Defects Prevention and Surveillance about how environmental exposures can contribute to birth defects and how we use birth defects data. During the presentation, the group discussed the data limitations, and our program manager was invited to join the Council to increase their capacity on how surveillance system improvements could benefit the public health system. Based in part on educational efforts by the Council and external partners, legislation was proposed and adopted with bipartisan support to amend state statute to make the registry an opt-out system.

## THE PUBLIC HEALTH IMPACT

This change will allow more accurate and complete surveillance of birth defects in Wisconsin. We will be able to include birth defect data on our portal so that the prevalence of birth defects can be compared with known and possible risk factors. With this change, researchers and public health professionals can also target education and outreach more effectively, leading to reduced birth defects in Wisconsin.



