The Birth Defects Project

Introduction

There are very few birth defects with a known definite link to environmental hazards. But being able to share data about when and where birth defects happen will help scientists and public officials understand whether these defects might be related to the environment and, if so, to take efforts to mitigate the potential public health problem. That is one of the main reasons for initiating this world-wide surveillance project. There does not exist, to date, a comprehensive birth defects reporting system that is accessible for information input to professionals and lay persons. This Geographic Information Systems (GIS) based application seeks to address this lacuna. Confidentiality of patients and data submitters, and security of data have been given prime consideration. All submitted patient data are aggregated to 10 degree latitude and longitude grids. Point level data are only visible to the person who entered these data. All other data show as aggregate data. A peer review process has been designed to enable one user who wishes to know more about data submitted by another user; an ability to send an email to the other user is incorporated into the system so that off- line collaborative efforts can be initiated. At a later stage of development of this site, such a real- time collaborative environment may be built into the interface. Currently, a link to such a collaborative environment (such as dedicated Yahoo or Google Groups) is proposed to be given. Administration of these sites would be on a user volunteer basis.

Background

Although there has been some research into how environmental hazards might cause birth defects, there is still much more work that needs to be done to understand the relationship of the environment to birth defects.

Birth defects are a large public health problem and are estimated to affect over 150,000 children in America every year. It is estimated that about 3% or one out of every 33 babies is born with a birth defect1. Birth defects are one of the leading causes of infant deaths. Babies born with birth defects have a greater chance of illness and long-term disability than babies without birth defects. Babies with birth defects are also more likely to be born preterm (before the 37th week of pregnancy) than babies without birth defects. Birth defects account for approximately 30% of all pediatric hospital admissions.

For some birth defects, doctors and public health scientists know how they happen and in some cases they can make recommendations to help prevent them. For many other birth defects, however, there are no clear causes. It is likely that most birth defects happen for

many reasons, not just one reason, and one of those reasons might be the environment.

In the United States, about 3% of babies are born with birth defects. Some women have a higher chance of having a child with a birth defect.

Women over the age of 35 years have a higher chance of having a child with Down syndrome than women who are younger.

If taken when a woman is pregnant, certain drugs can increase the chance of birth defects. Also, women who smoke and use alcohol while pregnant have a higher risk of having a baby with certain birth defects. Read more about alcohol exposed pregnancies. (embed: http://www.cdc.gov/ncbddd/fas/fasprev.htm)

Other women have a higher chance of having a baby with a birth defect because someone in their family had a similar birth defect.

Research about Birth Defects

CDC does research to try to find the causes of birth defects. CDC uses Basic Science research to study how chemicals in the air or water or land might harm a developing baby.

Others at CDC investigate what babies with certain birth defects have in common among them. They might study people's genes, their use of certain drugs, or their behaviors. Sometimes parents might be doing something that could harm a future baby.

CDC studies how behaviors, like drinking alcohol or taking certain drugs, can harm a baby. Based on their research CDC develops educational materials to explain to people what they can do, or not do, to try to have a healthy baby. CDC also works closely with doctors and other health care workers, schools, communities, and the media to help prevent birth defects.
Learn more about Birth Defects: http://www.cdc.gov/ncbddd/bd/facts.htm

Birth Defects Bibliography:

1. Birth Defects Res A Clin Mol Teratol. 2007 Feb; 79(2):65-186.

2. Erratum in: Birth Defects Res A Clin Mol Teratol. 2008 Jan; 82(1):41-62. Reporting birth defects surveillance data 1968-2003.

3. Correa A, Cragan JD, Kucik ME, Alverson CJ, Gilboa SM, Balakrishnan R, Strickland MJ, Duke CW, O'Leary LA, Riehle-Colarusso T, Siffel C, Gambrell D, Thompson D, Atkinson M, Chitra J.

INSTRUCTIONS for USE of the Birth Defects Tracker Application

Click on the following link to go to the Application:

http://birthdefectstracker.appspot.com/index.htm

A registered user, classified as "professional" or "other", using the provided tools, creates a point and/or an area of interest on the map. The application then associates this point or area of interest with information submitted by the user, using pre-configured drop-down lists of known birth defects and possible hazardous materials known to be associated with these defects. The ability to add birth defects, not found on the lists, is also included within the application. Additionally, the name and nature of the industry or commercial establishment in the vicinity of the report can also be entered. The application enables searching of the data by the hazardous chemical, by birth defect, by date, and by spatial selection of an area of interest. The resulting data are displayed on the map and on a table below the map with clickable links to appropriate actions.

1. Interface

1.1 The interface consists of

a. login and a "register" link on top right.

b. On the left, are the inter-active portions of the application.

i. Add Environmental Hazard
ii. Search Hazards
iii. Other fields associated with these hazards

b. Below, is the map interface for the application; this map initially shows the entire world with red bordered rectangles designating a color coded 10 degree by 10 degree latitude and longitude grid where the current user or others have previously entered birth defects information. These rectangles change to one degree by one degree grid(s) as you zoom in. This is aggregated information. No point locational information is visible or accessible to anyone at this stage.

2. Registration and Logging On

2.1 You do not need to be registered or logged in to search the map for any or all reported information in an aggregated form. Using the search box below the zoom bars on the left of the map, you can draw an area of interest and the table below will display with all the relevant information. The information displayed will

pertain to birth defects aggregated to ten degree by ten degree boundaries or one degree by one degree boundaries when you zoom –in further. You will not be able to see the exact locations of the birth defects but will see the extent of the polygons representing the environmental hazards. Be informed that the hazards data entry is available to any member of the public and may not be accurate or correct. Sometimes, a novice user will draw an out-of -position polygon.

3. Data Entry

3.1 In order to enter data, you must be registered. If you haven't already registered, register yourself.

i. To register, choose a login name and a password. Passwords are encrypted in the database in order to preserve the integrity of your data. (not even the database administrators of the site can get hold of your password, so make sure that you do not forget/lose the password or else you will lose your data – you are advised to make backups of your data on your local desktop system from time to time). At present, there is no functionality for confirming your email or to reset your password. Passwords must contain 6 characters or more.

ii. Check the box marked "medical professional" if you are one. If you are not a medical professional, leave this box unchecked. This information will be displayed for when another registered person needs to get in touch with you requesting details of your report(s).

3.2 To login, click on the "Login" link and enter your username and password, and click the submit button.

4. Tools

4.1 It is important that you become familiar with the tools provided for interacting with the map and data. The Tools available for inter-acting with the map interface are:

4.1.1 ***Pan Tool*** (default activation)

This tool is activated (your mouse pointer inherits this property) by default. Clicking and dragging this tool across the surface of the map moves the whole map in the direction of the movement of the mouse.

4.1.2 Point Placement tool

At the default zoom level of the world, the point placement tool is not visible. It is only available when you have zoomed in sufficiently for the tool to ensure accuracy in the placement of a point. This tool, when clicked on, changes the behavior of the mouse pointer to enable the user to click on a point of interest to

anchor the point. ***Make sure you are zoomed in sufficiently for this tool to be visible and to work***.

4.1.3 Polygon Drawing Tool

The polygon tool is also only available when the zoom level is sufficient to enable the user to accurately draw polygons of interest while entering the "hazards" information. Sequentially click and drag points and lines to complete the polygon with a double click.

4.1.4 Erase Tool

Clicking on this tool (**E**) enables the user to erase , on the map, a point or polygon that has been entered, but not yet saved. Sometimes the erase tool will appear to have erased other user entered features, but these will re-appear on refreshing the map.

4.1.5 Full Extent Tool

The Full Extent (**FE**) tool when clicked on enables the user to get a full vies of the map. This is particularly useful when the user has zoomed in so far that it is difficult to know where in the world one is.

4.1.6 Zoom Tools

These tools are part of the native Google map tools. Clicking on the "+" icon will enable the user to zoom-in, one click at a time.. Clicking on the "–"icon enables the user to zoom-out, one click at a time.

4.1.7 Spatial search Tool

This is a box that is labeled "Search" under the zoom tools. When the mouse is clicked on this box, it turns yellow, indicating that it is activated. Click and drag the mouse from the top left to the bottom right of your area of interest. This results in data from your defined area being returned as a table below the map

Hazard Concerns

A. You do not need to login to enter information regarding environmental hazards.

B. Click on "Add Env Hazard"

1. Using the Google map tools, zoom in to your area of concern. The more you zoom in, the more precise will be the relevance of your input

to the actual area of concern.

2. The polygon tool (on the right of the "hand" tool) will not be activated until a certain detail level is attained using the zoom tool. If you do not see the polygon tool, you are not zoomed in sufficiently. Using the "polygon" tool, delineate your area of concern by clicking and dragging several points and lines to complete the polygon of interest.

3. You can use the erase tool (E) to remove the polygon if it is unsatisfactory. You can do this many times until you finally save your work.. Once the Environmental Hazard concern has been submitted you will not be able to edit it.

4. Name: This should be a descriptive term for the industry or hazard you are concerned about

5. Enter the Industry Category – This is an auto prompt field and will suggest categories as you start typing the first few letters. You can also look up the North American Industry Classification (NAIC) codes by clicking on "NAIC" . Background information on these codes may be found here: http://www.epa.gov/tri/lawsandregs/naic/ncodes.htm

6. Enter a brief description of your concern in the box titled "Description". Maximum number of characters is 200.

7. The "Use Map to Identify Area" box will be auto-populated with the sequence of coordinates corresponding to your polygon's points (vertices). This box is for your reference; you may wish to copy and paste these coordinates in WORD or Notepad or a series of cells in an Excel spreadsheet on your desktop or local system, for future reference or for onward transmission.

8. Prior to Saving, make sure that the polygon is positioned and described correctly. If not, make changes in the text boxes to the text or to the positions by using the "Erase" (E) tool and then re-drawing the polygon again. When you use the Erase tool, other features such as rectangles and other polygons appear to be erased, but they will refresh after you have saved your new polygon.

9. Click on "Save" to log your entry into the database. You cannot make any changes to the polygon and the descriptive fields after you have saved it.

Birth Defects

A. You need to be registered and logged in for you to have the ability to enter information on your case. You are the "data owner" of the case information submitted by you.

B. Click on "Add person"

1. Zoom in sufficiently to be able to identify individual streets, and, if the satellite imagery is available, to features you recognize at almost the street level.

2. The "point" tool will not be visible and available for placing the location of your case until you have zoomed in sufficiently. When you see the "point" tool, (next to the "hand" tool"), you have zoomed in sufficiently. It is possible to zoom in further if you wish to. It is advisable that you zoom in as far in as you can for greater accuracy of placement. Use the "point" tool to place a point on the desired location. In this case, iot should be the location of the mother during the first trimester of pregnancy. Notice that the empty boxes for the Latitude and Longitude are now populated with the coordinates for the point you have placed.
3. If you wish to reposition the point, use the hand tool to move it around. If you wish to delete the point, use the "Erase tool" ()

4. Once you are satisfied with the placement of the point, go ahead and fill in the remaining fields:
    a. **NAME**: this field is for a unique identifier for your case. It could be numbers, letters or a combination of these. The purpose of this field is as a reference for three other pieces of functionality ; First, the amount of data that you enter is kept at a minimum on this application's database to maximize confidentiality and processor overheads. Second, this Unique ID/name will be used by those who can only see aggregated data within a one mile grid to reference the case (s) they are interested in in the email message piece. Third, you will be maintaining more detail on your individual cases on a spreadsheet or other tabular datasheet, this Unique ID will help merge the downloaded lat longs to your original, more extensive data for further analysis using GIS or other software.
    b. **LAT, LONG**: These two boxes are populated with the relevant

pairs of coordinates once your point has been placed. Later, you will be able to download your latitudes and longitudes along with some of the other data that you have entered for merging with other more extensive data that you might have on the case(s). The geocoded point is a value addition to you by using this interface.

c. **Date of Birth**: The Date of Birth can be entered by choosing the date from a calendar that pops up after clicking in the box .
d. **Birth Defect**: A list of Birth defects is available to select from. You can also enter any birth defects that do not appear in this list by clicking on the link "Add Defect"
e. **Save Person**: Make sure all the text and the point placement is to your satisfaction before you click on "Save person". If you need to alter the point or alter any text, you can do so before you save the person. At a later time, you have the ability to erase/delete your entry/entries (only your entry, not someone else's) in the "Search Persons" function.

C. Click on "Search Persons"

1. You have the ability to search using text or by interacting with the map, spatially.

TEXT SEARCH

2. Fill in the "date from" and "date to" fields using the pop-up calendar that appears when you click inside these boxes. The dates pertain to the date of birth entered while inputting the Birth defect information. This allows you to focus your search to a given time period of interest.
3. Birth Defect Type: allows you to input a specific type of birth defect you are interested in, from among all that have been submitted by all users of the system, or to narrow the search to specific subsets of this list by choosing the appropriate one(s)
4. Current User's Data: This is a check box field. When checked, the search results will only return the records you have entered. If left un-checked, the query will return all records in the space below.
5. Search Button: This completes your query and submits it to the system.

SPATIAL SEARCH

6. Using the "search" tool (the box labeled "search" below the zoom controls on the map) you can click and drag a rectangle sized according to the area of the parts of the world that you are interested in.

7. The results of the text or spatial search will be displayed in the space below the Map. This may take a variable amount of time based on the

complexity of the query and the number of records involved.

8. As soon as the query is executed, you will see "Search Download" link at the bottom of the map. When clicked you will be prompted to save a CSV file (open able in Excel) of all the search results that are displayed below this.

9. The search results have column headings that are the following:

    a. **Name** – This is populated by the "name" field in the "add-persons" function (B), above. The field will be populated by whatever was entered by you or any other person (if you unchecked the box in step 4 above. The field also serves to reference a case of interest should you anyone wish to correspond with the "owner" of this information. It is also used to merge, after download, data from your own tables to the added columns of lat and long available only in the downloaded file.

    b. **Birth Date/Hazard Type** –This column is populated by the Birth dates chosen. Hazard type is returned also if a spatial search was conducted and the hazard was also included in the spatial search (more on spatial search below)

    c. **Birth Defects/Hazard Desc**. Column is populated by the text that was either chosen from the list or was entered in the "add person" step

    d. **Map** – This is a link that when clicked locates the defect by zooming in to the appropriate grid of interest; If it was a defect submitted by someone other than you, you will only see the aggregated grid rectangle. If it was a defect(s) entered by you, you will see the point where you placed the defect.

    e. **Email** – This is a clickable link. Note that the email link does not appear for the cases entered by you. The email link is meant for use by those who wish to request the "owner" of the data for more information or for a collaborative understanding. In the email dialog box that opens up when you click on this link, you would fill in a Subject such as "Birth defect Tracker Request", and then proceed to make your request and also entering your contact information. Note that you will not have access to the "owner's" email address. Neither will any others have access to your email address when corresponding with you for a similar request. This is so that email and identities of the data owners are kept confidential and private. If you wish to divulge your email address or other personal details, it is your responsibility to do

so. Requesting the data owner for more information or for any other collaborative endeavor is left entirely up to the individual parties concerned. You may wish to reference the case(s) by suing the Birth date and Name/ID field. If the data owner wishes to correspond with you, they will. If they don't, they might not. Future functionality for this site includes an ability to carry on an open discussion in a forum style interface, but until then, this will have to be the chief mechanism for communication between individuals registered at this site. A separate Yahoo groups or Google Groups could be created, with a link embedded within this application, for this purpose. This will depend on the demand for such functionality within this interface. Complete the email process by clicking on either "submit" or "close"

f. **Edit** – Note that only your records are editable. Clicking on "edit" brings up the details you entered in the text boxes on the left of the map. You can make changes here and then re-submit. Perhaps you would like to move or delete the point, perhaps the defect needs to be changed etc. etc.

g. **Delete** – Deletes the record. Use cautiously since records once deleted can not be recovered.