



National Birth Defect Registry

Established 1990

Sponsored by Birth Defect Research for Children, Inc.

A 501(c) (3) Non-profit



Why the registry was created

History/concept

The [National Birth Defect Registry](#) was developed by Birth Defect Research for Children (1986-1990) as an alternative form of research to rapidly identify patterns of birth defects with similar exposures in the prenatal and/or pre-conceptual parental histories. These patterns define hypotheses for further study through more traditional and highly controlled forms of research.

This [concept](#) grew out of a study of how the major causes of environmental birth defects (teratogens) had been discovered. Teratogens like thalidomide, rubella, Dilantin, DES, alcohol, methyl mercury, radiation and others had all been first identified by a process called “the alert practitioner”. This involved doctors reporting an increase in a (usually rare) birth defect occurring over a defined period in their patient population. Retrospective investigation into the histories of maternal exposures focused on an exposure they all had in common. This initial hypothesis was then verified by other forms of research: animal, cell culture, case control.

Development

The National Birth Defect Registry was designed to expand the concept of the “alert practitioner” to a national scale by creating a comprehensive inter-relational data base that would collect birth defect/ developmental disorder information as well as genetic, health and exposure data from families all over the country.

The development of the registry was funded by seed grants from the American Legion Child Welfare Foundation and Beyond Pesticides. The registry concept was endorsed and the questionnaire design was reviewed and modified through the collaboration of a scientific board representing experts in Biometrics, Human Development, Endocrinology, Environmental Epidemiology, Biochemistry, Genetics, Environmental Biology and Obstetrics & Gynecology. These scientists included Peter Kahn, PhD, Rutgers; James Murphy, PhD, University of Colorado; Theo Colborn, PhD, World Wildlife Fund; Stuart Newman, PhD, New York Medical College; Shanna Swan, PhD, California Department of Health; Maureen Paul, M.D. University of Massachusetts and Wayland Swan, PhD, Eco Logic Company.

The original questionnaire was designed in a 16-page booklet form like a scan-able test. The data from the questionnaire were hand-entered into an inter-relational data base through a computer form adapted from the questionnaire. Approximately 4,000 cases were collected in this format.

Internet Adaptation

In 2004, BDRC received a grant from the Mitchell Kapor Foundation to adapt the project to the internet. This offered much more flexibility in adding new categories of birth defects and/or exposures to the questionnaire. The on-line registry also allowed families to enter data that is directly downloaded into the main data base without the need for a data entry person. There is also a great savings in postage and printing costs. The on-line registry currently has 4668 cases, but the numbers increase each day. BDRC is also in the process of entering the original 4000 cases into the on-line registry.

The on-line questionnaire for the registry collects data on both maternal and paternal genetic and health histories as well as exposures to medications and environmental toxins. Special sections have been created to collect [military exposure information](#) for Vietnam and Gulf War veterans. These sections were developed through collaboration with the New Jersey State Agent Orange Commission and from data on Gulf War exposures from the General Accounting Office.

Both structural (i.e. cleft palate, spina bifida) and functional birth defects (i.e. learning and attention disorders, autism, immune dysfunction) are included on the registry form. Conditions are arranged by broad category headings with "other" columns in each category for conditions that may not appear on the registry form. Periodically the "other" columns are evaluated to see if additional conditions should be added to the form.

Outreach

Parents learn about the registry through Public Service Announcements, magazine ads, listings in national and state databases, web searches, referrals from national organizations and parent support groups, veterans' groups and medical professionals.

A new form of registry outreach is our [Community Resource Center](#) which offers services for communities with concerns about increases in birth defects and developmental disabilities.

[Birth Defect Investigations through the Registry](#)

Some of the national birth defect issues investigated through registry research include the following:

- [Bendectin](#) was an anti-nauseant medication on the market from 1956-1982 recommended solely for morning sickness in pregnancy. The drug was a combination of an antihistamine, an antispasmodic and vitamin B-6. Bendectin (or its ingredients) was associated with birth defects, childhood cancers and SIDS in human case reports , animal and epidemiological studies. Registry data confirmed increases in upper limb reduction deformities, clubfoot, cleft lip and palate, abnormal teeth and other conditions that were suggested in other studies of Bendectin and/or its ingredients. Bendectin was taken off the worldwide market in 1982.

- **Agent Orange** was a defoliant widely used in Vietnam and some other countries. Ingredients include 2-45T, 2-4D and the toxic by-product TCDD (dioxin). Studies have found that TCDD targets the immune system; causes ectodermal effects; neurobehavioral effects; thyroid problems; abnormal teeth and learning disabilities. Analysis of data in the National Birth Defect Registry found impressive increases in learning and attention disorders; neurobehavioral conditions; skin disorders; immune disorders; thyroid and abnormalities of tooth development in the children of Vietnam veterans. BDRC's work on identifying birth defects in veterans' children helped lay the ground work for the recent [law passed](#) requiring the Veterans' Administration to study the effects all toxic exposure during military service on the children and grandchildren of veterans, whether deployed or serving stateside.
- **Gulf War.** A year after veterans started returning home from the first Gulf War, BDRC began to receive reports of birth defects in their children. According to the General Accounting Office, veterans of the first Gulf War may have been exposed to over 31 reproductive toxicants. The birth defect registry's scientific board suggested adding a special section of the registry to collect data on the military exposures and birth defects being reported. One rare birth defect (Goldenhar Syndrome) was alarmingly increased as were other categories of more common birth defects. BDRC was asked to present the data on Gulf War birth defects to the Presidential Advisory Board on Gulf War Illnesses. A Department of Defense study later confirmed a tripling of Goldenhar Syndrome in the children of Gulf War veterans whose babies were born in military hospitals. Half of babies with Goldenhar in the registry were born in civilian hospitals so we were convinced that the rate increase would be even stronger if all cases were included.
- **Goldenhar Study with University of Texas, SW** – Dr. Robert Haley, the head of epidemiology at the University of Texas, SW is a leading researcher on Gulf War Syndrome. He requested that our organization collaborate with him on a study of the Goldenhar cases we had found in the children of Gulf War veterans. After consultation with our scientific board, we agreed. Our part of the study was to do additional outreach to craniofacial groups to be sure we had located as many cases as possible; get IRB consent forms signed by the parents; conduct an additional telephone interview with the parents and acquire copies of medical records confirming the diagnosis of Goldenhar Syndrome. Dr. Haley's department is in charge of the rest of the study. This study is still ongoing.

- **Dickson Cleft Palate Cluster**. The Tennessee Department of Environment and Conservation referred a grandmother from Dickson, Tennessee to our offices because she was concerned that there were too many cases of cleft palate in her community. We sent registry questionnaires into the community and working with several community advocates, we identified a cluster of 18 cleft palate cases over a three-year period in a birth population of less than 1800. Statistically, less than 2 cases would have been expected. Most of these families lived near an uncapped and unlined landfill where local companies had dumped barrels of the solvent, TCE. Over time the TCE leaked into their community water supply. We worked with the EPA for an evaluation of the situation. The Center for Disease Control also later confirmed the cluster of cleft palate cases we had found. The landfill was subsequently capped; the community water source changed and residents were warned not to drink untested private well water.
- **Joplin, Missouri** –The United Steelworkers asked BDRC to review birth defect data from Joplin MO. The incidence of birth defects in Joplin was higher than the county and the state of Missouri. Our review found that there were significant increases in certain categories of birth defects (especially Atrial Septal Defects of the heart). BDRC joined with the United Steelworkers and other children’s advocacy groups in asking the governor of Missouri to request further studies.
- **Alaska** – Alaska Community Action on Toxics asked BDRC to participate in a review of data and a conference call with community members and scientists. Alaska Native community representatives were concerned about a report from the health department that birth defects in Alaska were double the rate of other states. There was also an increase in certain birth defects in Alaska Native communities near open waste dumps. Prior to the call, BDRC reviewed all the data on birth defects in the area. One problem, we discovered was that Alaska has required reporting of birth defects by health care facilities and providers for children up to age six. Birth defect reporting systems that have required monitoring out to six years will usually show double the rate of birth defects found in systems that use only hospital discharge data. Despite this, there was a four-fold increase in the rate of other congenital defects in infants born to Alaska Native mothers residing in villages with high hazard dumpsite contents.

- **Gastroschisis** is a stomach defect that is increasing in worldwide reporting systems. Initially, NIOSH (National Institute on Occupational Safety and Health) requested information from BDRC on gastroschisis cases in our registry that they could compare with increases they were finding in certain industrial settings. Later, as the number of cases in the registry grew, BDRC provided data on 252 gastroschisis cases compared to 229 cleft palate cases in the registry for a collaborative study with Dr. Niel Dalal at the University of Texas. This study found gastroschisis was associated with young maternal age, alcohol and/or recreational drug use in early pregnancy. These findings are consistent with the published literature on gastroschisis. This helped to demonstrate that the National Birth Defect Registry can find birth defect and exposure associations that are the same as much more expensive and time-consuming studies.
- **ASD Report** – Autistic Spectrum Disorders (autism, Asperger's, PDD, PDD NOS) are neurobehavioral disorders that are increasing in incidence. According to the CDC, the prevalence of autism has increased 289.5% over the last 12 years. We analyzed data on 137 ASD cases in our registry and reported some intriguing findings. Sixty percent of our ASD cases occurred in children with other structural birth defects suggesting that in these cases, the ASD was part of a birth defect sequence. Over 20% of the children with an ASD also had a sibling with a structural birth defect, but no ASD. BDRC is currently doing outreach to ASD organizations to increase the number of cases in the registry so that we can conduct a re-analysis to determine if these original findings continue to be supported. A recent analysis of 301 cases also found a 60% rate of association between ASDs and structural birth defects. This could suggest new directions for autism research.

Supporting Documents

Environmental Health Perspectives

Birth Defect Research for Children's Executive Director was asked to review an article on "Environmental Factors in Birth Defects" that was published in the October edition of *Environmental Health Perspectives*, the journal of the National Institute of Environmental Health Sciences. Below is an excerpt from the article:

"Betty Mekdeci, executive director of the advocacy group Birth Defect Research for Children, says there are many problems with the basics of how birth defects are tracked and evaluated. Her experience of more than 30 years—prompted by her efforts, and those of her husband, to figure out why their son was born with multiple birth defects led her to conclude that some of the most important limitations include inadequate medical diagnostic codes for classifying many birth defects, inaccurate use of codes by health care practitioners to meet insurance billing requirements, and the inability of many health care practitioners to diagnose a birth defect at birth or in follow-up visits, and skepticism toward the input of parents, who usually know better than any one doctor about the full range of health problems their child is having.

To overcome some of these problems, Mekdeci and her colleagues have developed an alternative method of tracking birth defect incidence based on parent responses to a lengthy questionnaire. About 6,000 completed questionnaires have been collected since 1990. Mekdeci and her staff analyze the questionnaire responses for patterns, and she reports they have identified about half a dozen clusters so far. Although the group readily acknowledges these are self-reports from a self-selected population, some of the clusters have later been confirmed by various government agencies. For instance, in Dickson, Tennessee, they detected a cleft palate cluster that was confirmed by the CDC. The group sees its role as identifying birth defect cases and then encouraging health agencies to investigate."

Scientific Findings and Recommendations
Research Advisory Committee on Gulf War Illnesses
November 17, 2008
(Birth Defect Section from 465 Page Report)

Another innovative approach for assembling and evaluating data on birth defects was presented to the Committee by Ms. Betty Mekdeci. Ms. Mekdeci directs Birth Defect Research for Children (BDRC), a private nonprofit organization that maintains special registries of children with birth defects, including children of Gulf War veterans. The analytic approach of the organization involves comparing proportional patterns of birth defects in different populations, in order to raise hypotheses about potential problems in a given group. BDRC has identified a number of problems that appear to disproportionately affect the over 3,000 children in their birth defect registry. This includes 33 children with Goldenhar syndrome—substantially more cases than had been identified in the large military hospital study. BDRC data also indicates that the majority of identified children with Goldenhar Syndrome born to Gulf War veterans were born in 1992 and 1993, with fewer cases born after 1993.

Dickson Tennessee Cleft Palate Cluster

“Since May 2000, BDRC has been diligently working on finding the cause of so many birth defects here in Dickson. There have been 18 Children born with cleft lip and palate over the last three years as well as a rise in the number of children identified with autism and other neurological disorders. BDRC has helped document this cluster of birth defects through their National Birth Defect Registry. They have also been persistent in researching toxins released by industries in the county.”*Deanna Stephens, Foundations Early Intervention Services.*



Robert W. Haley, M.D.
Professor of Internal Medicine
U.S. Armed Forces Veterans
Distinguished Chair for Medical Research,
Honoring America's Gulf War Veterans

Department of Internal Medicine
Division of Epidemiology and
Preventive Medicine

March 12, 2008

Betty Mekdeci
Executive Director
Birth Defect Research for Children
800 Celebration Ave., Suite 225
Celebration, FL 34747

Dear Betty:

I want to thank you and your organization, Birth Defect Research for Children, for the excellent collaboration you have provided in our joint study of birth defects in children born after the 1991 Gulf War to Gulf War veteran parents. Your contributions to our national research effort have been essential and extremely valuable because of your own personal commitment to serving the children of veterans affected by birth defects.

Ten years ago when the question of whether birth defects were elevated in the postwar children of Gulf War veterans and several government-funded studies failed to answer the question, I learned of your efforts to bring to public consciousness the unusually high rate of the Goldenhar complex of birth defects in veterans' children. I contacted you and found you eager to collaborate in a project to study the problem definitively.

According to the scientific design of our study, you contacted every organization in the country that provides family support services to the families of children with the Goldenhar birth defect to identify all the cases of this rare condition in the country. This was a highly ambitious undertaking, but with your excellent list of organizations and the respect you have gained over your years of service to these organizations and their families, you contacted all of them and generated a list of all the Goldenhar cases in the country—a most laudable feat. You also collected key information that qualified each one as a bonafide case and obtained their permission to be contacted for a study.

I am now in the process of contacting all of these families to collect epidemiologic data and a blood sample to compare the prevalence of Goldenhar complex birth defects and various risk factors in the Goldenhar parents who were deployed to the Gulf War versus those who were not deployed. If I am successful, we will determine definitively whether there is a link between Gulf War deployment and Goldenhar birth defects in later offspring.

Joplin, Mo

Fox News Fox4kc.com

April 2009

Steelworkers Call for Investigation into Joplin Birth Defect Numbers

(Joplin, MO) The Steelworkers Union is calling on Governor Jay Nixon for an investigation and action on the rising incidence in Joplin of birth defects and chronic diseases, which may be associated with industrial pollution.

The call for government action accompanies release of a public health report - using public health data available from the Missouri Department of Health and Senior Services (MDHSS) - on the high incidence of birth defects and chronic diseases. Diseases include cancer, strokes, and diseases of the heart, respiratory system and immune system.

The report was produced by the United Steelworkers, which represents 250 workers at the Eagle Picher Technologies, LLC battery plant in Joplin, a military contractor, and hundreds of others in the area.

They say MDHSS data shows rapidly rising rates of birth defects in recent years for Joplin residents.

Betty Mekdeci of Birth Defect Research for Children said that, statewide, the incidence of birth defects rose from 571 per 10,000 births in 1999-2001 to 601.9 in 2003-2005. In Joplin, birth defects per 10,000 births rose from 557 in 1999-2001 to 793.1 in 2003-2005.

That means that for every 1,000 babies born in Joplin, 16 more babies suffer with birth defects than in the rest of the state, according to this government data.

In addition, the "Chronic Disease Profile for Joplin Residents" section of the report shows Joplin residents with a significantly higher rate of death, hospitalization and emergency room visits compared to residents in the rest of Missouri.

The health report notes the long history of lead mining and smelting and other industrial activity in the area, and its legacy of soil and water pollution. Lead causes a wide range of birth defects, as do other contaminants from lead smelting.

The Union is fighting efforts by management at eagle Picher to cut back family health care benefits for employees at the producer of batteries and energetic devises for the defense, space and commercial industries.

Autistic Spectrum Disorders Report

From HealthNewsDigest.com

Children's Health
High Rates of Birth Defects Found in Autistic Children
Jan 19, 2010 - 10:00:11 AM

New Birth Defect Research Reveals Craniofacial & Brain Defects Among Children with Autistic Spectrum Disorders



(HealthNewsDigest.com) - CELEBRATION, Fla., -- Nearly two-thirds of the children with Autistic Spectrum Disorders recorded in the National Birth Defect Registry (NBDR) also suffer from structural birth defects, according to the national nonprofit, Birth Defect Research for Children (BDRC). The group reported that most of the defects affect the face, head and central nervous systems of newborns.

Birth Defect Research for Children, a national nonprofit founded in 1982, maintains the registry to collect data from parents on all kinds of structural birth defects and functional deficits including autistic spectrum disorders. Betty Mekdeci, executive director of BDRC explains, "We designed the registry with a collaboration of prominent scientists. The registry's extensive data allows researchers to identify possible patterns underlying the incidence of birth defects as well as prenatal conditions and exposures. We are asking all parents of children with structural and functional birth defects to contact us to register for our database to continue this study."

"Our current data suggests that genetic and environmental triggers may interact to account for the increase in ASDs. We need to collect more data to confirm the pattern we are seeing."

The new analysis reveals that over 60% cases also had structural birth defects, primarily Central Nervous System (CNS) or Craniofacial Defects. The other 40% of the ASD cases reported associated developmental problems, but no reported structural birth defects.

Most frequent CNS disorders reported were Microcephaly (small head), Cerebral Palsy, Chiari Malformation (a structural defect of the brain) and Absent or Thin Corpus Callosum (the band connecting the two halves of the brain), The most frequent Craniofacial Defects included Low Set Ears, Partial Hearing Loss, Abnormal Teeth and Abnormal Facial Structure.

The registry also collects data on prenatal exposures to medications, illnesses and toxins. The most frequently reported maternal exposure was acetaminophen (AP). AP use has increased in recent years. Recent studies have reported associations between maternal AP ingestion and childhood asthma and a stomach defect called gastroschisis.

The full report is available on-line in the Environmental Reports section of Birth Defect research for Children's website at http://www.birthdefects.org/research/ASD_Report_2009.pdf



LITANY OF BIRTH DEFECTS

Since 1990, Birth Defect Research for Children has collected data on birth defects and developmental disabilities in the children of Vietnam veterans. The National Birth Defect Registry is a collaboration among seven prominent scientists to identify patterns of birth defects and disabilities in children with similar prenatal exposures.

When compared to non-veterans' children in the registry, the children of Vietnam veterans have shown consistent increases in learning, attention, and behavioral disorders; all types of skin disorders; problems with tooth development; allergic conditions and asthma; immune system disorders including chronic infections; some childhood cancers; and endocrine problems including thyroid disorders and childhood diabetes. More and more studies of prenatal exposures to dioxins and similar chemicals are adding support for these associations.

According to Linda Birnbaum of the U.S. Environmental Protection Agency, dioxin can modulate growth and development. In the embryo and fetus, dioxin-altered programming can result in malformations, anomalies, fetal toxicity, and functional and structural deficits that often are not detectable until later in life.

In a paper published in *Environmental Health Perspectives*, Birnbaum discusses research that demonstrates that prenatal exposures to endocrine disruptors (chemicals that can disrupt hormone activity) such as TCDD can alter hormones, reproductive tissue development, and increase susceptibility to potential carcinogen exposure in the adult.

Increased susceptibility to chronic childhood infections and cancers later in life may be a result of dioxin's effects on the developing immune system. Researchers in 2000 investigated the immunological effects of everyday exposures to PCBs and dioxins in preschool-age Dutch children. The researchers found that prenatal exposure to these chemicals was associated with changes in the T-cell population. They concluded that the effects of prenatal background exposure to PCBs and dioxins persist into childhood and could be associated with a greater susceptibility to infectious disease.

Another 2003 study by a team of researchers from Quebec reported their finding of a chemical imbalance that could be a marker for prenatal immune damage caused by organochlorines (which include dioxin-like compounds). The researchers found that the lymphocyte cells of newborns exposed to higher concentrations of these chemicals during prenatal development secreted fewer cytokines than those of a control group of newborns. These alterations of the immune system could lead to increased susceptibility to infection.

A growing body of evidence is linking prenatal exposures to dioxin-like chemicals to learning and behavioral deficits. At a Children's Health Meeting

in 2000 sponsored by the National Institute of Environmental Health Sciences, Jerry Heindel reported on several studies of pregnant women who had consumed several meals of PCB-contaminated fish per month during pregnancy and who gave birth to infants with small but detectable learning and behavioral deficits. The children with the highest exposure averaged six points lower in IQ compared to children with lower levels of exposure.

EPA Letter

UNITED STATES ENVIRONMENTAL PROTECTION AGENCY
NATIONAL HEALTH AND ENVIRONMENTAL EFFECTS
RESEARCH LABORATORY V •• RESEARCH TRIANGLE PARK, NC 27711

OFFICE OF
RESEARCH AND DEVELOPMENT

February 27, 2012

Betty Mekdeci
Executive Director
Birth Defects Research for Children
976 Lake Baldwin Lane, Suite 104
Orlando, FL32814

Dear Ms. Mekdeci,

Thank you for your correspondence and for the work done by your organization on behalf of the health of children. As you know, the Environmental Protection Agency has been on the forefront of dioxin research and regulation for many years. We are pleased to have been able to finalize and release the updated non-cancer science assessment for dioxins. As a result of our past efforts, dioxin emissions in the United States have been reduced by over 90%.

Yet, we understand that the effects of exposures in the past, including exposures of Vietnam veterans, are still of great concern. Your birth defects registry is the type of effort needed to make linkages between environmental exposures and birth defects. Causality is difficult to prove in epidemiological studies, so the larger and better defined the population being studied, the stronger the case will be. I encourage you to publish findings from your studies in the open scientific literature, where it will have the greatest impact.

We are also beginning to understand that the range of possible effects of exposures during pregnancy or early childhood goes far beyond structural birth defects and includes functional, physiological, and other effects that may not manifest until later in life. The EPA supports an active research program in this area through the EPA/NIEHS Children's Environmental Health and Disease Prevention Research Centers (www.epa.gov/ncer/childrenscenters/) as well as in our intramural research programs. Protecting the health of our children will always be a priority for us.

Again, I applaud the hard work you and your organization do every day to protect and improve the lives of our children. We certainly share your passion for that. Best wishes for continued success in your efforts.

Sincerely,
*UC
Harold Zenick, Ph.D.
Director

Scientific Advisory Board

In early 1990, BDRC brought together seven prominent scientists working in the fields of developmental genetics, biometrics, obstetrics & gynecology, reproductive epidemiology, endocrine research and expertise in the toxic effects of dioxin. The scientific board evaluated and added areas to the registry questionnaire and endorsed the concept of pattern identification as a valid approach to reaching hypotheses about birth defects associated with specific exposures.

Theo Colborn, Ph.D.

Dr. Colborn was Founder and President Emerita of The Endocrine Disruption Exchange (TED) and Professor Emerita of Zoology at the University of Florida, Gainesville. She was an environmental health analyst, best known for her studies on the health effects of endocrine disrupting chemicals. In 1991, as a fellow of the W. Alton Jones Foundation, she brought a group of 21 scientists with diverse backgrounds together, to attend the first of a series of conferences at Racine, Wisconsin, that became known simply as "Wingspread", about the effects of human exposure to hormone-disrupting chemicals examined in the environment. (Dr. Colborn died in 2014.)

James Murphy, Ph.D.

Dr. Murphy served as an Associate Professor, Department of Preventive Medicine & Biometrics, and University of Colorado Health Sciences Center. He received his doctorate in Biostatistics from Johns Hopkins University. He served as acting Chairman for the Department of Preventive Medicine & Biometrics at the University of Colorado. He co-authored papers on questionnaire and database design and data management. (Dr. Murphy died in 2010.)

Peter Kahn, Ph.D.

Dr. Kahn is Associate Professor of Biochemistry at Rutgers University. A graduate of Harvard and Columbia University, Dr. Kahn has been Session Chair for the sixth, seventh, eighth and tenth international symposia on dioxins. Dr. Kahn has been a principal investigator for research measuring dioxins and dibenzofurans in blood and tissue of Vietnam veterans as well as immunological markers.

Stuart Newman, Ph.D.

Dr. Newman is Professor of Cell Biology, Anatomy and Medicine, New York Medical College. He also serves on the Board of Directors of the Council for Responsible Genetics and has been on advisory panels for the National Institutes of Health Study Sections on Reproductive Biology and Craniofacial Anomalies. Newman has been awarded research grants for the study of chondrogenesis, morphogenesis and cartilage differentiation.

Wayland Swain, Ph.D.

Dr. Swain received his doctorate in environmental biology and health from the University of Minnesota School of Public Health; was a Fellow of the Royal Society of Health in London and was listed in American Men and Women of Sciences. He served as Associate Professor and Head of the Department of Preventive Medicine at the University of Minnesota. (Dr. Swain died in 2003.)

Shanna H. Swan, Ph.D.

Dr. Swan has a doctorate in statistics from the University of California, Berkeley. She currently is a Professor of Environmental Medicine & Public Health, Professor of Obstetrics, Gynecology and Reproductive Science at Mt. Sinai School of Medicine. Dr. Swan has worked for over twenty-five years to understand the threats posed by chemicals to our environment and our health, and, when necessary, to develop new paradigms to assess their risks.

Maureen Paul, M.D.

Dr. Paul is an obstetrics & gynecology specialist in Boston, MA and has been practicing for 34 years. She graduated from Tufts Univ Sch of Med in 1979 and specializes in obstetrics & gynecology, occupational medicine, and more.

Additional Scientists Added to Scientific Advisory Board

Janette D Sherman, MD

Dr. Sherman served as an adjunct professor, Dept. Sociology, Western Michigan Univ. Kalamazoo, MI. She specializes in internal medicine, occupational medicine and toxicology. Dr. Sherman worked as a biologist and chemist for the Atomic Energy Commission, the U.S. Navy Radiological Defense Laboratory and Michigan State University. She has also been a consultant to NIOSH and the EPA for the Toxic Substance Control Act and for the Office of Pesticides.

Carol Kwiatkowski, Ph.D.

Dr. Carol Kwiatkowski is the Executive Director of TEDX, The Endocrine Disruption Exchange, and an Assistant Professor Adjunct at the University of Colorado Boulder. TEDX is a science-based non-profit organization dedicated to compiling and disseminating scientific evidence on the health and environmental damage caused by low-level exposure to endocrine disrupting chemicals.

Rodney Dietert, Ph.D.

Dr. Rodney Dietert is Professor of Immunotoxicology at Cornell University in Ithaca, New York. He received his PhD in immunogenetics from the University of Texas at Austin. In 2015, Dr. Dietert received the James G. Wilson Publication Award from the Teratology Society for the best paper of the year on the microbiome.

Current Registry Support

The operation of the National Birth Defect Registry is supported by public donations, Combined Federal Campaign donors, foundation grants and university or state contracts in the case of collaborative studies.

What is in the Future?

The National Birth Defect Registry is constantly evolving and improving. Because nearly half of the visits to BDRC's web sites are made on cell phones, the registry needs to be redesigned to be cell-phone friendly. We also need to be current with the latest in database technology.

As new issues arise, BDRC also needs to add new sections to the registry questionnaire. One example of this is monitoring the possible reproductive effects of fracking (non-conventional gas extraction). There are studies suggesting that living near fracking sites can expose families to known reproductive-hazards and these effects need to be measured.

To encourage participation from exposure or condition specific groups, we would also like to design customized entry pages to the registry for groups like veterans, parents of children with Autistic Spectrum Disorders, etc.

BDRC has also added a section to our web site called the [Community Health Resource](#). This is a place where communities who are concerned that there are excess cases of birth defects and/or childhood cancers in their area can contact BDRC to plan an investigation similar to the one that was done to identify the cleft palate cluster in Dickson, Tennessee. We want to be able to help communities at no charge, so we need to build a fund that will cover this work that can take several years.

Since associations between birth defects and exposures are most effectively identified by sufficient numbers of cases, BDRC needs to increase outreach to families across the country. Today, this is most effectively and economically accomplished by targeted Facebook campaigns and Search Engine Optimization that directs families to our web site. Both of these endeavors work faster with a sufficient budget.

Support Your National Birth Defect Registry

BDRC is starting an initiative to raise funds to support "Your National Birth Defect Registry". We say "your" because this project is not supported by federal funding or any special interest. It is entirely independent so the results from research done through the registry are autonomous.

We have developed levels of support and will list your name (unless you prefer to be anonymous) on our web site and in this registry report.

When you donate to support the registry, you are donating to a better future for all children, because "every birth defect has a cause" and we are committed to discovering these causes.