



BIRTH DEFECT



RESEARCH FOR CHILDREN

National Birth Defect Registry

- Based on concept of "alert practitioner"
- Identifies patterns of birth defects with the same or similar exposures
- Collects data on maternal/paternal pre-conceptual and prenatal exposures
- Cases dually identified by individual symptoms and overall syndrome or category name
- Designed to raise hypotheses



Teratogens Identified by Alert Practitioners

- Thalidomide
- Rubella
- Dilantin
- DES
- Alcohol
- Methyl Mercury
- Radiation

Scientific Advisory Board

- Peter Kahn, Ph.D.
Rutgers University
- James Murphy, Ph.D.
University of Colorado
- Theo Colborn, Ph.D.
World Wildlife Fund
- Stuart Newman, Ph.D.
New York Medical College
- Shanna Swan, Ph.D.
California Department of
Health Services
- Maureen Paul, M.D.
University of Massachusetts
- Wayland Swain, Ph.D.
Eco Logic Company
- Janette Sherman, M.D.
Wayne State University

Registry Projects

- Bendectin
- Agent Orange
- Gulf War
- Community based
 - Dickson, TN - oral cleft cluster
 - Apopka, FL - lupus cluster

BIRTH DEFECT RESEARCH CENTER, INC. REGISTRY QUESTIONNAIRE

(Please print in blue or black ink or no.2 pencil)

Date: / / Reporting person's name: _____

Relationship to child: mother stepmother grandmother other: _____
 father stepfather grandfather

Street/POB: _____ Apt No: _____

City: _____ State: _____ Zip: _____

Phone: (____) _____

Name and number of someone who can always get in touch with you. Name: _____

Phone: (____) _____

I would like to be matched with other families of children with similar disabilities. yes no

CHILD DISABILITIES INFORMATION

Child's name: _____

Sex: Male Female Blood Type: O A B AB Rh+ Rh- Race: Asian or Pacific Islander Black (non-Hispanic) Hispanic Native American or Alaskan Native White (non-Hispanic) Other (please specify): _____

Date of birth: / / Place of birth: / /

Birth weight: lbs. oz. Child's age at birth (months of gestation):

Do the father and mother of this child have other biological children* who do not have birth defects? *Do not include children from other marriages. yes no don't know

If yes, please list date of birth and sex for each one:

DOB: / / Male Female
 DOB: / / Male Female
 DOB: / / Male Female

Were child's disabilities diagnosed by a: physician teacher other: _____
 psychologist social worker

Are medical or school records available confirming child's disabilities? yes no don't know

Would you be willing to be contacted for further research? yes no don't know

Has your child died? yes no If yes, list Cause _____ and Date / /

CHILDHOOD DISABILITIES

Please fill in the bubble by each condition your child has. If your child has a condition that is not listed, write the name of the disability in the OTHER space in the appropriate column.

Central Nervous System (CNS)

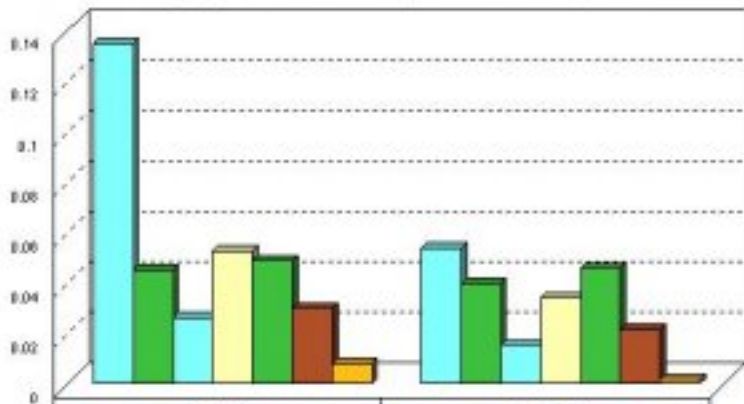
- | | |
|---|---|
| <input type="radio"/> A001 anencephaly
<input type="radio"/> A002 microcephaly
<input type="radio"/> A003 hydrocephaly
<input type="radio"/> A004 polycephaly
<input type="radio"/> A005 Arnold Chiari malformation
<input type="radio"/> A006 cortical blindness
<input type="radio"/> A007 encephalocele
<input type="radio"/> A008 absence corpus callosum
<input type="radio"/> A009 spina bifida | <input type="radio"/> A010 spina bifida occulta
<input type="radio"/> A011 holoprosencephaly
<input type="radio"/> A012 seizure disorder
<input type="radio"/> A013 Dandy Walker malformation
<input type="radio"/> A014 tuberous sclerosis
<input type="radio"/> A015 ataxia
<input type="radio"/> A016 cerebral palsy
<input type="radio"/> A017 other CNS |
|---|---|

Bendectin

- Anti-nauseant - 1956-1982
- Antihistamine/antispasmodic/B-6
- Birth defects
- SIDS
- Childhood cancers

Birth Defect Research for Children, Inc.

National Birth Defect Registry - Bendectin Exposed vs Non-exposed

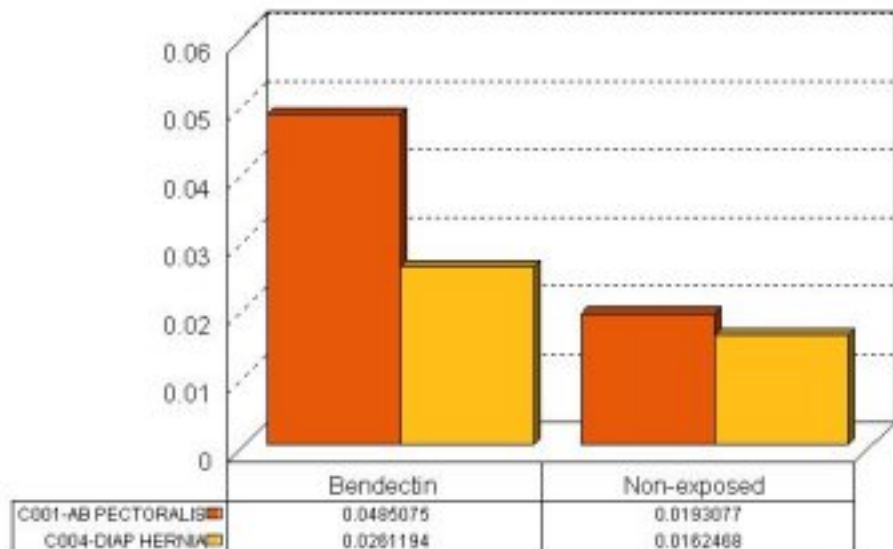


	Bendectin	Non-Exposed
B001-UP LIMB RED	0.1343264	0.053685
B002-LOW LIMB RED	0.0447761	0.0395573
B005-TWIST LOW LIMB	0.0261194	0.0190695
B006-DISLOCATED HIP	0.0522368	0.0339063
B008-CLUBFOOT	0.0489075	0.0495793
B009-CLUB W/DEF	0.0298507	0.0211914
B016 TAR	0.007627	0.0016482

N=4515 Bendectin : 268 NON-BDN: 4247 FILE: LIMB 5/02

Birth Defect Research for Children, Inc.

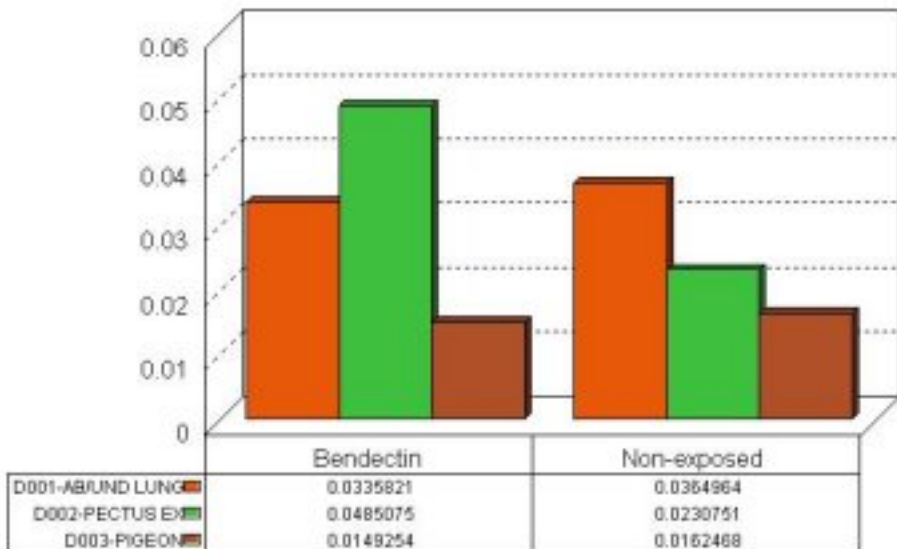
National Birth Defect Registry - Bendectin Exposed vs Non-exposed



N=4515 BDN: 268 NON-BDN: 4247 FILE: MUSCLE 5/02

Birth Defect Research for Children, Inc.

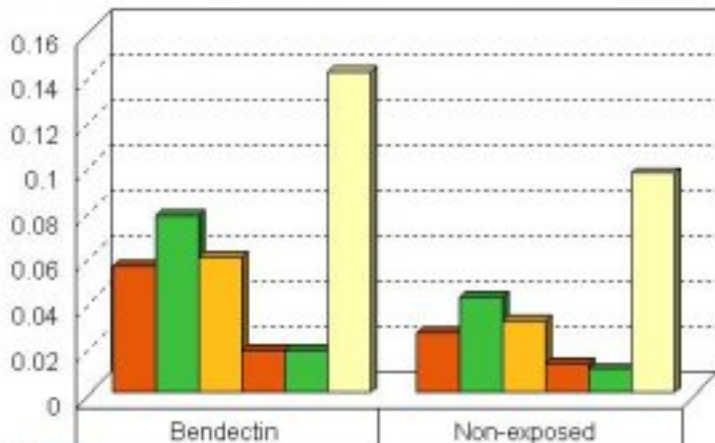
National Birth Defect Registry - Bendectin Exposed vs Non-exposed



N=4515 BDN: 268 NON-BDN: 4247 FILE: CHEST 5/02

Birth Defect Research for Children, Inc.

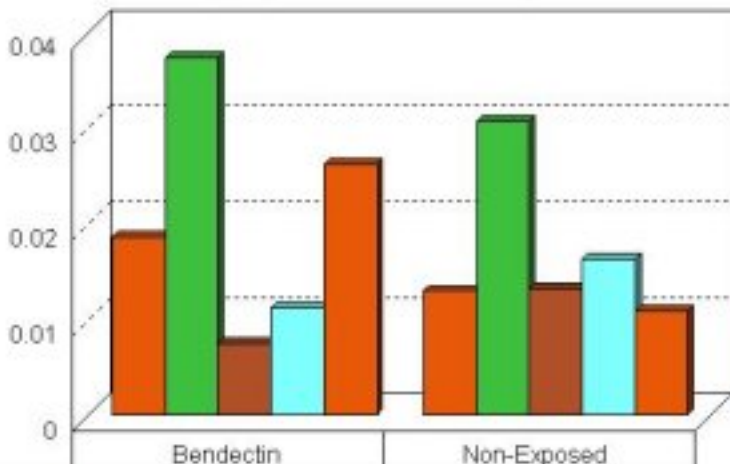
National Birth Defect Registry - Bendectin Exposed vs Non-exposed



	Bendectin	Non-exposed
H001-CLEFT LIP	0.0559701	0.026607
H002-CLEFT PALATE	0.0783582	0.0423829
H004-MICROGNATHIA	0.0597015	0.0317871
H007-CRANIOSYNOSTOSIS	0.0186567	0.0129503
H008-MACROGLOSSIA	0.0186567	0.0103603
H012-ABNOM TEETH	0.141791	0.0967742

Birth Defect Research for Children, Inc.

National Birth Defect Registry - Bendectin vs Non-Exposed

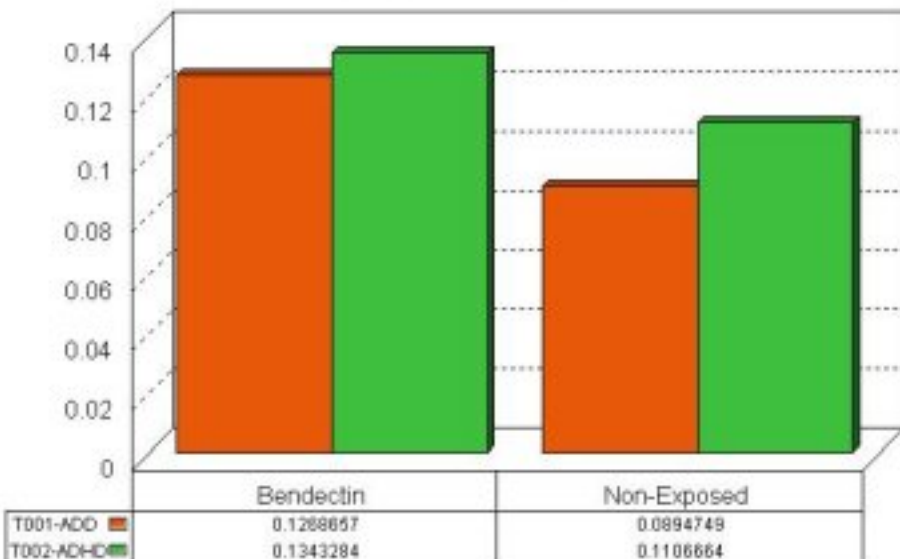


	Bendectin	Non-Exposed
L001-HYPOSPADIUS	0.0186567	0.0129503
L002-UNDES TESTICLES	0.0373134	0.0306098
L003-ABS KIDNEY	0.0074627	0.0131858
L011-MALF SEX ORG	0.0111194	0.0162488
L013-HYDROCELE	0.0261194	0.0108312

N=4515 BDN: 268 NON-BDN: 4247 FILE: GU 5/02

Birth Defect Research for Children, Inc.

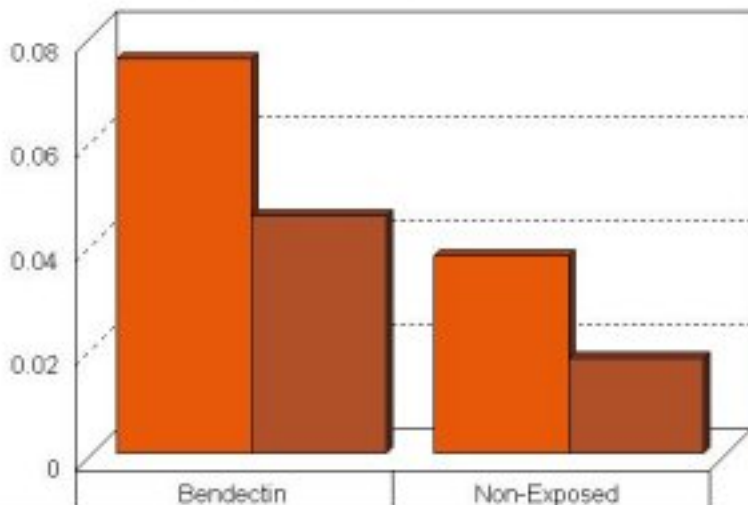
National Birth Defect Registry - Bendectin Exposed vs Non-Exposed



N=4515 BDN: 268 NON-BDN: 4247 FILE: ATTENTION DIS 5/02

Birth Defect Research for Children, Inc.

National Birth Defect Registry - Bendectin Exposed vs Non-Exposed



Y001-EARLY PUBERTY
Y003-THYROID DEF

0.0754717

0.0454545

0.0376737

0.0181304

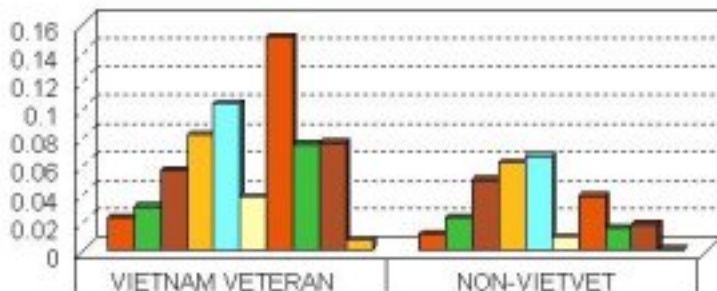
N=4515 BDN: 268 NON-BDN: 4247 FILE: ENDOCRINE 5/02

Agent Orange

- 2-45T/2-4D/TCDD
- TCDD targets immune system
- Ectodermal effects
- Neurobehavioral effects
- Thyroid defects
- Abnormalities of teeth
- Alterations in learning

Birth Defect Research for Children, Inc.

National Birth Defect Registry - Children of Vietvets/Non-vets

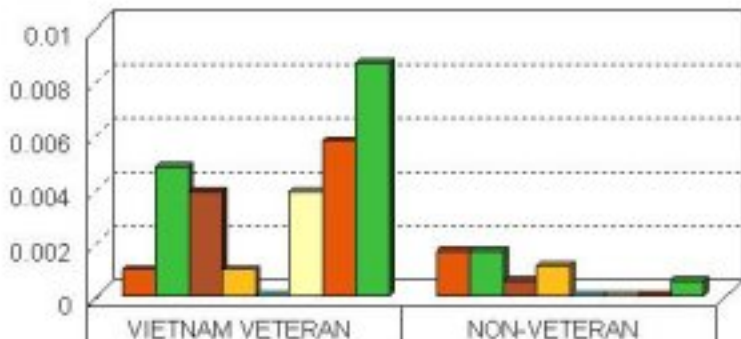


M001-PORT WINE	0.0229446	0.0114691
M002-CAFE AU LAIT	0.0305927	0.0229383
M003-STRAWBERRY	0.0564054	0.0491535
M004-OTHER BIR MARK	0.081262	0.0617149
M005-ECZEMA	0.1032505	0.0660841
M006-PSORIASIS	0.0372849	0.0092845
M007-ACNE RASH	0.1500956	0.0376843
M008-SKIN FUNGUS	0.0745698	0.0152922
M009-SKIN COLOR CHANG	0.0755258	0.0180229
M010-LAMELLAR ICHTHY	0.0066922	0.0005461

N=2877 VETERAN: 1046 NON-VET: 1831 FILE: SKIN 3/02

Birth Defect Research for Children, Inc.

National Birth Defect Registry - Children of Vietvets/Non-vets

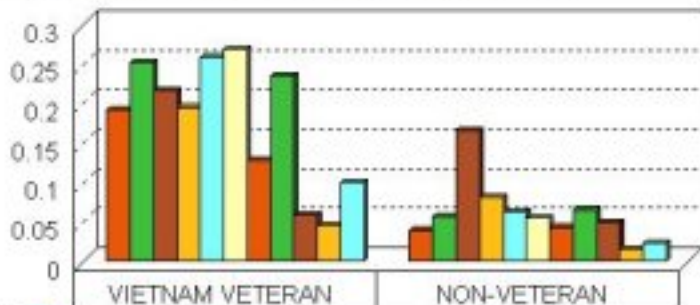


	VIETNAM VETERAN	NON-VETERAN
P001-NEUROBLASTOMA	0.000956	0.0016384
P002-LEUKEMIA	0.0047801	0.0016384
P003-LYMPHOMA	0.0038241	0.0005461
P004-WILMS TUMOR	0.000956	0.0010923
P005-COLON CANCER	0	0
P006-HODGKINS	0.0038241	0
P007-NON-HODGKINS	0.0057361	0
P008-SARCOMA	0.0086042	0.0005461

N=2877 VETERAN: 1046 NON-VET:1831 FILE: CANCER 3/02

Birth Defect Research for Children, Inc.

National Birth Defect Registry - Children of Vietvets/Non-vets

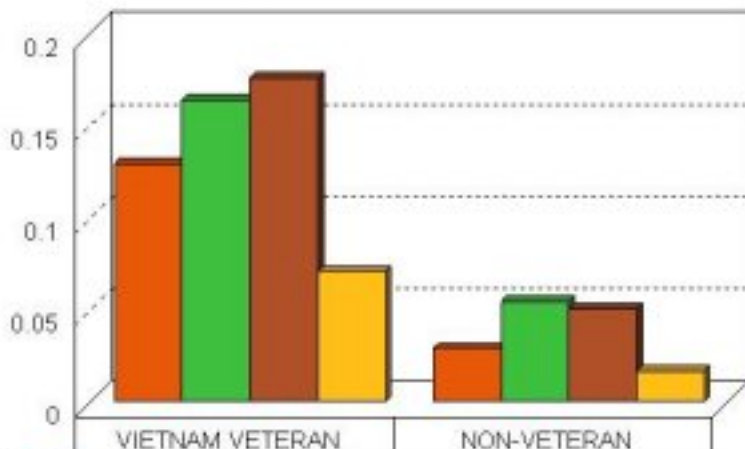


	VIETNAM VETERAN	NON-VETERAN
S001-DYSLEXIA	0.1912046	0.0387766
S002-MATH	0.260478	0.0557073
S003-SPEECH	0.2151052	0.1649372
S004-LANG PROCESS	0.1940727	0.080284
S005-SPELLWRITE	0.2571702	0.0622611
S006-MEMORY	0.2676864	0.054615
S007-AUD PROCESS DEF	0.1271511	0.0420535
S008-COMPREHENSION	0.2342256	0.0644457
S009-SENS INTEGR DYS	0.0583174	0.0486073
S010-PERSERVERATION	0.0449331	0.014746
S011-VISUAL MEMORY DEF	0.0994264	0.0223921

N=2877 VETERAN: 1046 NON-VET: 1831 FILE: LD 3/02

Birth Defect Research for Children, Inc.

National Birth Defect Registry - Children of Vietvets/Non-vets

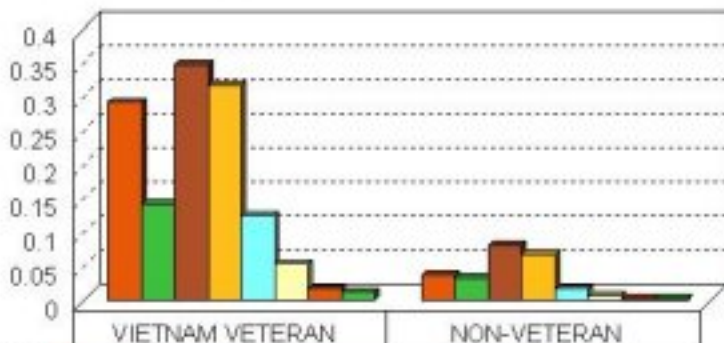


T001-ADD	0.1290631	0.0289459
T002-ADHD	0.1634799	0.0540688
T003-DISTRACTIBILITY	0.1759082	0.0502458
T004-HYPOACTMTY	0.0707457	0.0163845

N=2877 VETERAN: 1046 NON-VET: 1831 FILE: ATTENTION DIS 3/02

Birth Defect Research for Children, Inc.

National Birth Defect Registry - Children of Vietvets/Non-vets

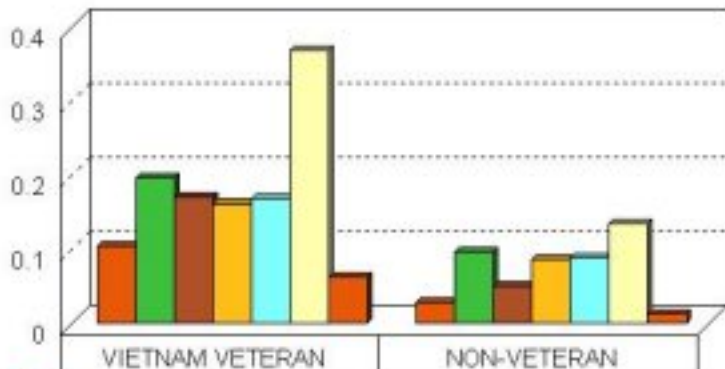


	VIETNAM VETERAN	NON-VETERAN
V001-DEPRESSION	0.289675	0.036592
V002-OB/COMPULSIVE	0.1405354	0.0316767
V003-MOOD SWINGS	0.3460803	0.0791917
V004-ANGER	0.3145315	0.0671764
V005-BREAKS LAW	0.123327	0.0158383
V006-BORDERLINE PERS	0.0525813	0.0054615
V007-SCHIZOPHRENIA	0.0152064	0.0021846
V008-DYSTHYMIA	0.0114723	0.0021846

N=2877 VETERAN: 1046 NON-VET: 1831 FILE: EMOT/BEHAVIORAL 3/02

Birth Defect Research for Children, Inc.

National Birth Defect Registry - Children of Vietvets/Non-vets

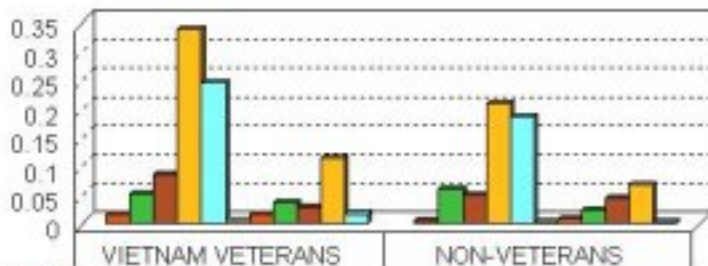


	VIETNAM VETERAN	NON-VETERAN
W001-HIVES	0.1032505	0.0273075
W002-ASTHMA	0.1959847	0.0961223
W003-HAYFEVER	0.1692161	0.0496996
W004-FOOD SENS	0.1606119	0.0846532
W005-DRUG REACTION	0.167304	0.0868378
W006-ALLERGIES	0.3680688	0.1338067
W007-MCS	0.0621415	0.0120153

N=2877 VETERAN: 1046 NON-VET: 1831 FILE: ALLERGIES 3/02

Birth Defect Research for Children, Inc.

National Birth Defect Registry - Children of Vietvets/Non-vets

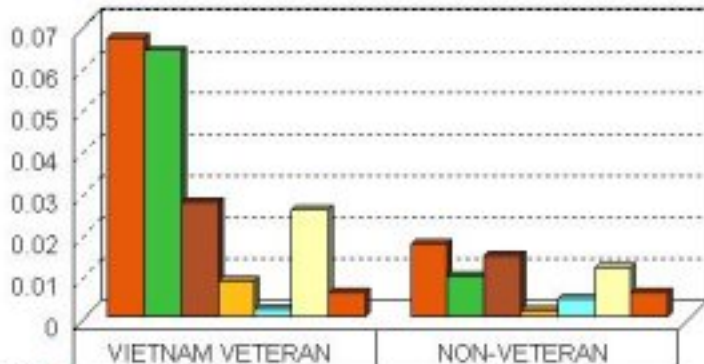


	VIETNAM VETERANS	NON-VETERANS
X001-PRIMARY IM DEF	0.0162524	0.0049153
X002-PNEUMONIA	0.0516252	0.0606226
X003-URINARY INFECT	0.0860421	0.0496996
X004-UP RESPIR INFEC	0.3374761	0.2091753
X005-EAR INFECT	0.2447419	0.1851447
X006-HYPOGAMMAGLOB	0.0057361	0.0032769
X007-CHRONIC VIRUS	0.0152964	0.0087384
X008-IMMUNE DEFECIENCY	0.0372849	0.0245767
X009-THRUSH	0.0277247	0.0447843
X010-UNEXPLAIN FEVERS	0.1128107	0.0677226
X011-AUTOIMMUNE DIS	0.0172084	0.0032769

N=2877 VETERAN: 1046 NON-VET: 1831 FILE: IMMUNE 3/02

Birth Defect Research for Children, Inc.

National Birth Defect Registry - Children of Vietvets/Non-vets

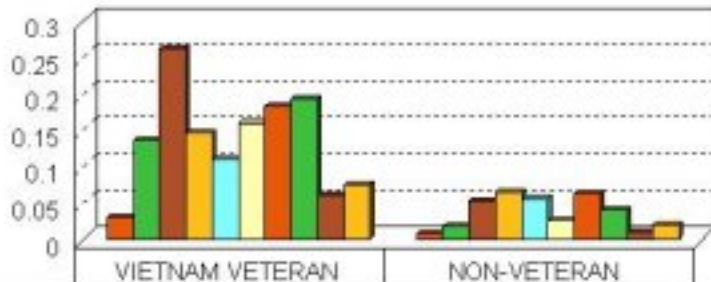


	VIETNAM VETERAN	NON-VETERAN
Y001-EARLY PUBERTY	0.0669216	0.0174768
Y002-DELAY PUBERTY	0.0640535	0.0098307
Y003-THYROID DEF	0.0277247	0.014746
Y004-DIABETES	0.0086042	0.0016384
Y005-DIABETES INSIPIDUS	0.001912	0.0043692
Y006-HYPOGLYCEMIA	0.0258126	0.0120153
Y007-PITUITARY DEF	0.0057361	0.0060076

N=2877 VET: 1046 NON-VET: 1831 FILE: ENDOCRINE 3/02

Birth Defect Research for Children, Inc.

National Birth Defect Registry - Children of Vietvets/Non-vets



	VIETNAM VETERAN	NON-VETERAN
Z001-ENDOMETRIOSIS	0.0286807	0.0070999
Z002-MENSTRUAL PROB	0.1357553	0.0180229
Z003-HEADACHES	0.2609943	0.0518842
Z004-HEAT/COLD SENS	0.1453155	0.0644457
Z005-LIGHT SENS	0.1080306	0.054615
Z006-CHRONIC FATIGUE	0.1586998	0.0251229
Z007-MUSC PAIN/WEAK	0.1826004	0.0628072
Z008-JOINT PAIN	0.1921606	0.0387766
Z009-ARTHRITIS	0.0602294	0.0067384
Z010-HHR LOSS	0.0745698	0.0185691

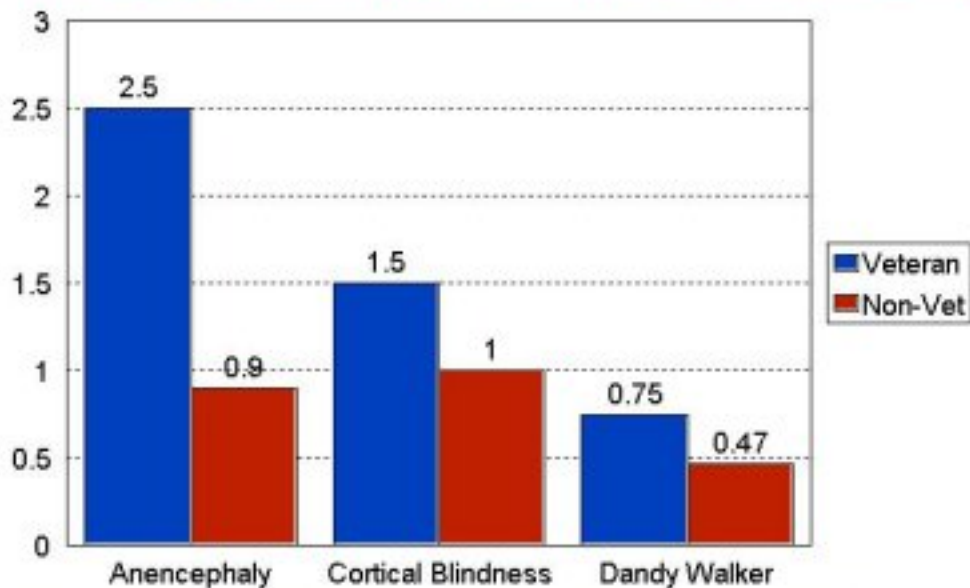
N=2677 VETERAN: 1046 NON-VET: 1831 FILE: MISC(1) 3/02

Gulf War Exposures

- DEET
- Permethrin
- Pyridostigmine
- Pentachlorophenol
- Benzocaine sulfur
- Aluminum phosphide
- Baygon
- Boric Acid
- Sevin
- Amidinohydrazone
- Diazinon
- Dursban
- Dichlorvos
- Ficam
- Carbaryl
- Lindane
- Malathion
- Oil Well Fires
- Leaded fuels
- Depleted Uranium
- Solvents
- Decontam agent
- Malaria Pills
- Campfires
- Leishmaniasis
- Chemical warfare agents
- CARC
- Vaccinations
- D-phenothrin
- Allethrin
- Paint
- Others

Birth Defect Research for Children, Inc.

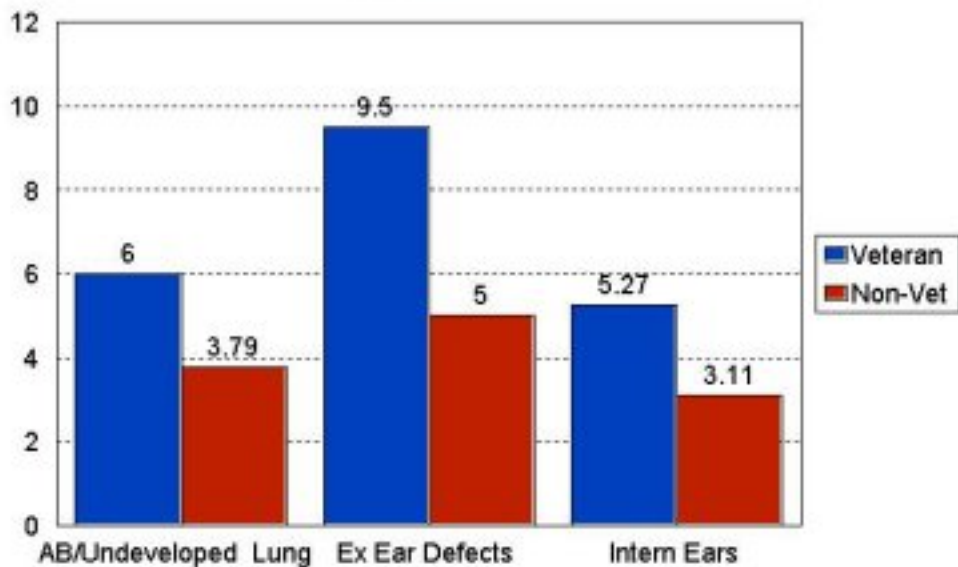
National Birth Defect Registry - Children of Gulf Vets/Non-Vets



N=2902 VETERAN 398 NON-VET: 2503 - CNS Comp Cases per 100

Birth Defect Research for Children, Inc.

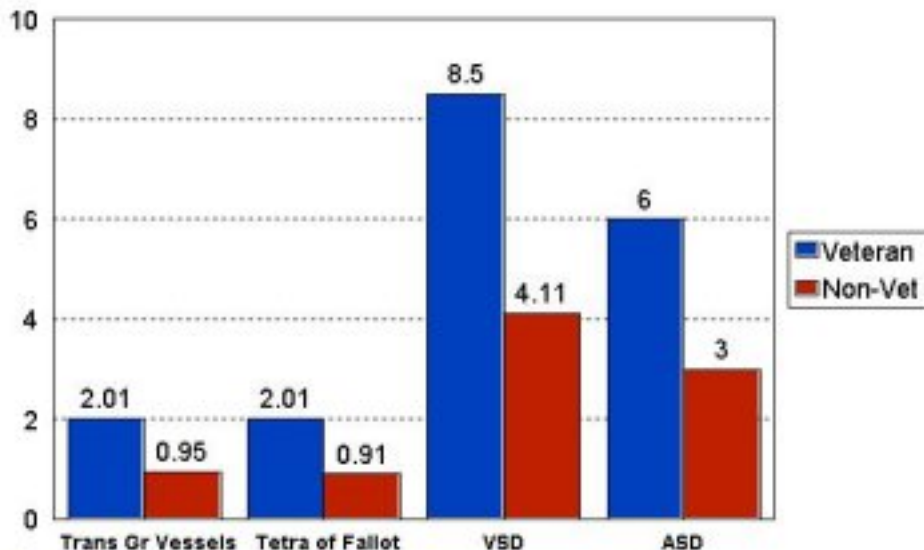
National Birth Defect Registry - Children of Gulf Vets/Non-vets



N=2902 VETERAN 398 NON-VET: 2503- Lung/Ear Comp Cases per 100

Birth Defect Research for Children, Inc.

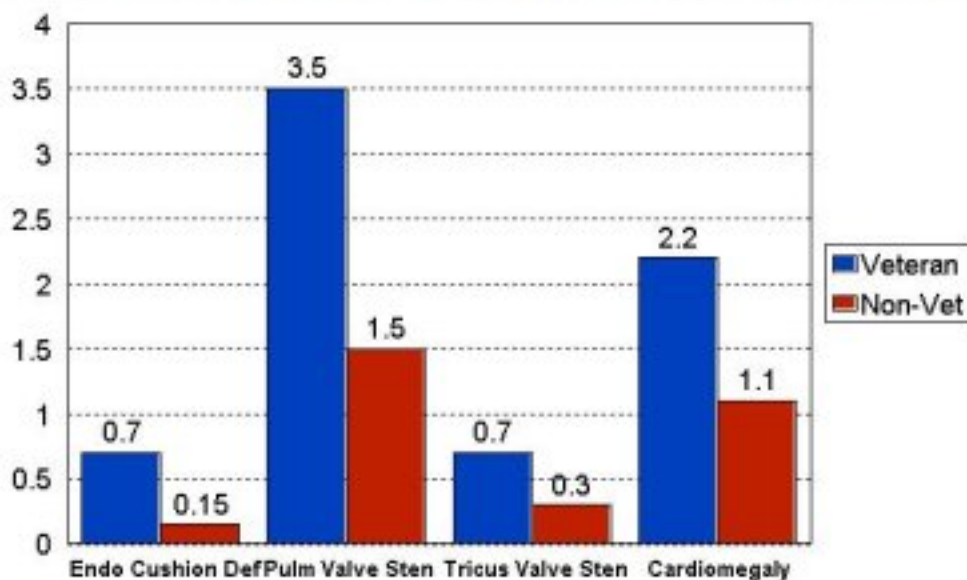
National Birth Defect Registry - Children of Gulf Vets/Non-vets



N=2901 Veteran; 398 Non-vet; 2503 - Heart Defects

Birth Defect Research for Children, Inc.

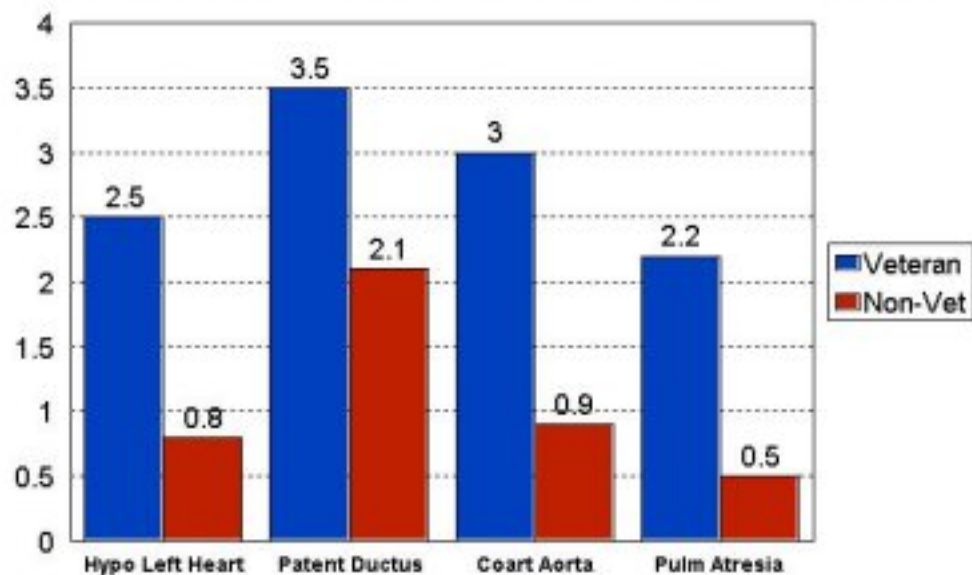
National Birth Defect Registry - Children of Gulf Vets/Non Vets



N= 2901 Veteran: 398 Non-Vet: 2503 Heart Defects Cases per 100

Birth Defect Research for Children, Inc.

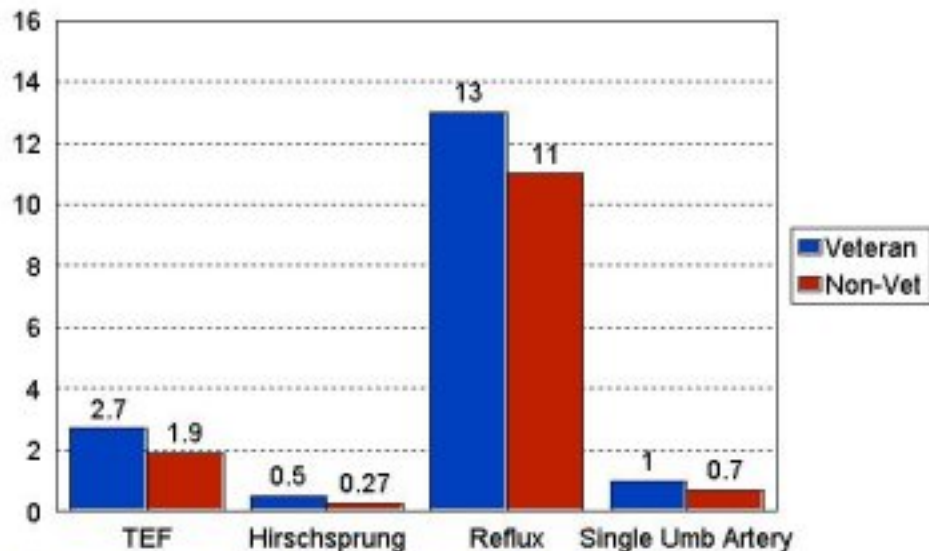
National Birth Defect Registry - Children of Gulf Vets/Non-Vets



N= 2901 Veteran: 398 Non-Vet: 2503 Heart Defects Cases per 100

Birth Defect Research for Children, Inc.

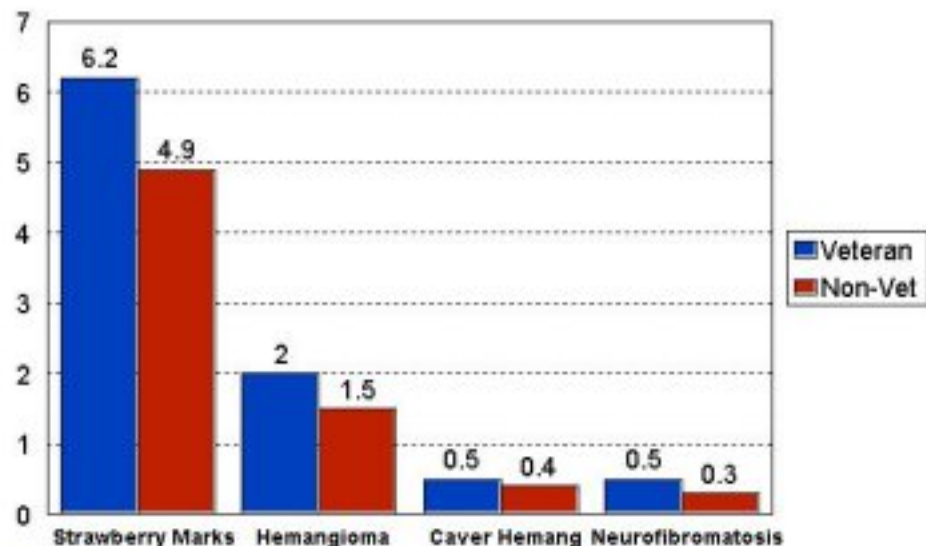
National Birth Defect Registry - Children of Gulf Vets/Non-Vets



N=2901 Veteran: 398 Non-Vet: 2503 GI Comp Cases per 100

Birth Defect Research for Children, Inc.

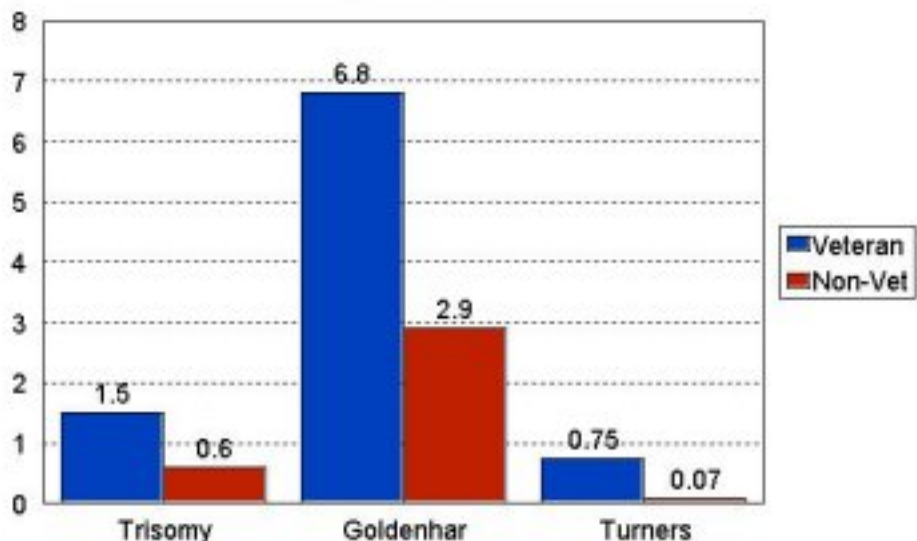
National Birth Defect Registry - Children of Gulf Vets/Non-Vets



N=2901 Veteran: 398 Non-Vet: 2503 Skin/Tumors Cases per 100

Birth Defect Research for Children, Inc.

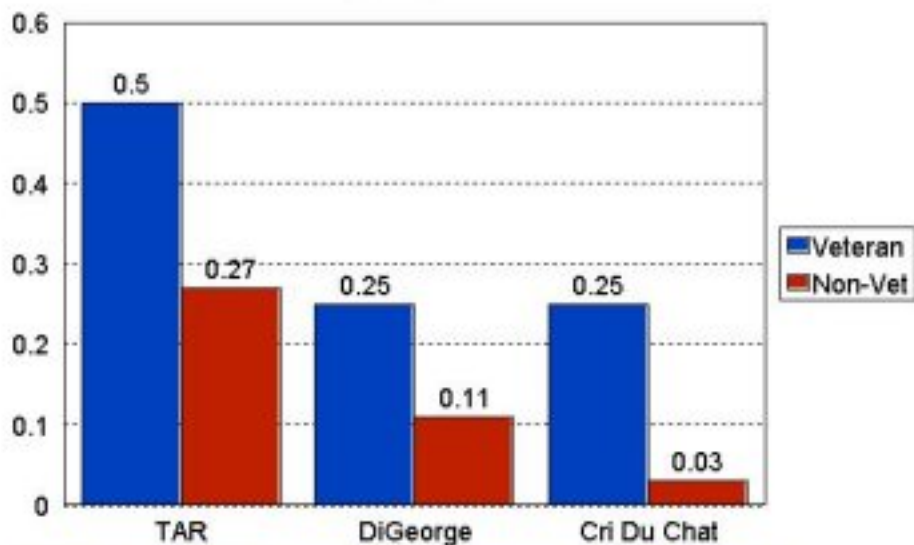
National Birth Defect Registry - Children of Gulf Vets/Non-Vets



N=2902 Veteran 398 Non-Vet 2503- Syndromes Comp Cases per 100

Birth Defect Research for Children, Inc.

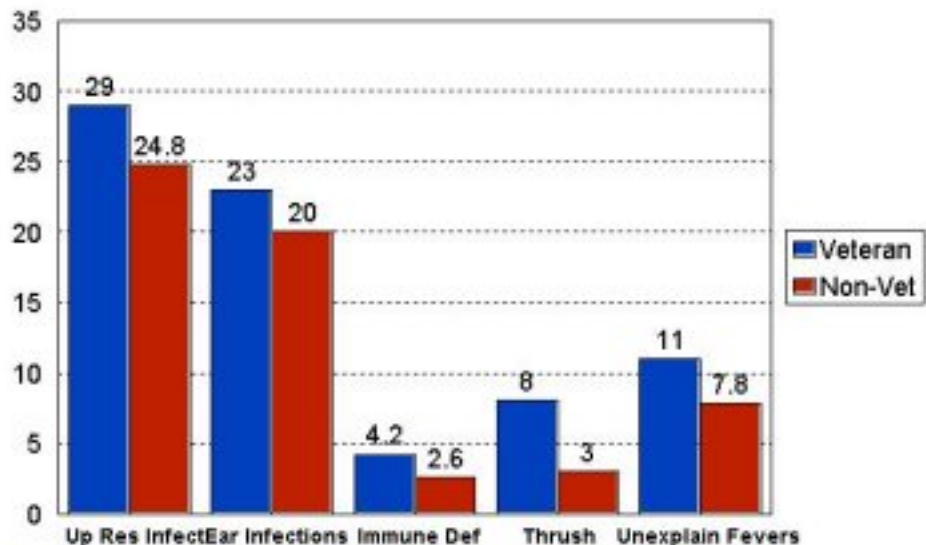
National Birth Defect Registry - Children of Gulf Vets/Non-Vets



N+2902 Veteran 398 Non-Vet: 2503 - Syndromes Comp Cases per 100

Birth Defect Research for Children, Inc.

National Birth Defect Registry - Children of Gulf Vets/Non-Vets



N=2902 Veteran 398 Non-Vet: 2503 - Immune Comp Cases per 100

Dickson Cleft Palate Investigation

- 19 cases of cleft palate/2 expected
- TCE leachate from old landfill
- Toluene emissions from printing company
- Excessive Trihalomethanes in water
- CDC confirmed cluster
- EPA contracted new report on landfill
- Landfill now capped
- Tennessee legislature voted to move source of community's water to a different river



NBDR Can Be A Tool for Birth Defect Prevention

- Generates hypotheses for further research
- Gives families a role in research and prevention
- A tool for community investigation
- The ultimate source for exposure information
- Low cost of operation

“because every birth defect has a cause”