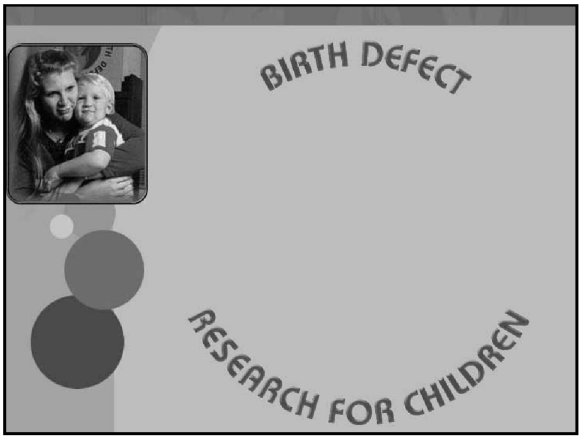
Presentation 2 – Betty Mekdeci



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
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  University of Massachusetts
- Wayland Swain, Ph.D.
  Eco Logic Company
- Janette Sherman, M.D.
  Wayne State University

BIRTH DEFECT RESEARCH FOR CHILDREN, INC.
REGISTRY QUESTIONNAIRE
(Please print in blue or black ink or no.2 pencil)

Date: ___/___/___ (Mo Day Yr) Reporting person's name:
Relationship to child: ○ mother ○ father ○ stepmother ○ stepfather ○ grandmother ○ grandfather ○ other: _____
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: ___/___/___ (Mo Day Yr) Place of birth: _____ (City) / _____ (State)
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: ___/___/___ (Mo Day Yr) ○ Male ○ Female
DOB: ___/___/___ (Mo Day Yr) ○ Male ○ Female
DOB: ___/___/___ (Mo Day Yr) ○ Male ○ Female
Were child's disabilities diagnosed by a: (please mark all that apply) ○ physician ○ psychologist ○ teacher ○ social worker ○ other: _____
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 ___/___/___ (Mo Day Yr)

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)

○ A001 anencephaly
○ A002 microcephaly
○ A003 hydrocephaly
○ A004 porencephaly
○ A005 Arnold Chiari malformation
○ A006 cortical blindness
○ A007 encephalocele
○ A008 absence corpus callosum
○ A009 spina bifida
○ A010 spina bifida occulta
○ A011 holoprosencephaly
○ A012 seizure disorder
○ A013 Dandy Walker malformation
○ A014 tuberous sclerosis
○ A015 ataxia
○ A016 cerebral palsy
○ A017 other CNS

Page 2

Registry Projects

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

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

Gulf War Exposures

- DEET
- Permethrin
- Pyridostigmine
- Pentachlorophenol
- Benzocaine sulfur
- Aluminum phospide
- 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

Disability Frequency

Resp. Infect.	117	VSD	35
Ear Infect.	92	Drug Reaction	34
Motor Delay	86	Hypotonia	34
Colic as Baby	62	Seizures	33
Speech	62	Acne-like Rash	33
Allergies	57	Thrush	32
Jaundice	56	Mood Swings	32
Reflux	52	Pneumonia	29
Heart Murmur	51	Birth Mark	28
High Fevers	46	Stomach problems	28
Ext. Ears	40	Sleep disorder	26
Asthma	38	Walks on tiptoes	26
Food Sens.	38	Goldenhar	26
Eczema	35	Up. Limb Reduction	25

Male-Mediated Birth Defects

Evidence from Experimental and Epidemiological Studies

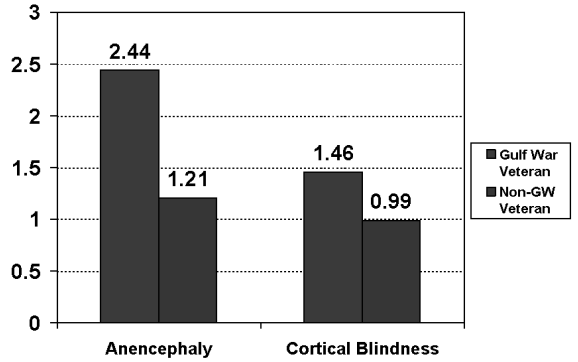
- Toluene
- Benzene
- Lead/mercury
- Trichloroethane
- Solvents
- Dyes
- Cigarette smoke/alcohol
- Drugs

Possible Outcomes

- Congenital malformations
- Spontaneous abortions
- Low birth weight
- Childhood cancers
- Developmental, neurobehavioral, neuroendocrine, neurochemical abnormalities

Birth Defect Research for Children, Inc.

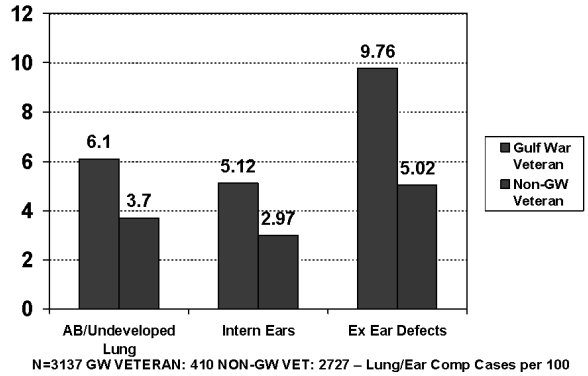
National Birth Defect Registry – Children of GW Vets/ Non-GW Vets



N=3137 GW VETERAN: 410 NON-GW VET: 2727 – CNS Comp Cases per 100

Birth Defect Research for Children, Inc.

National Birth Defect Registry – Children of GW Vets/ Non-GW Vets



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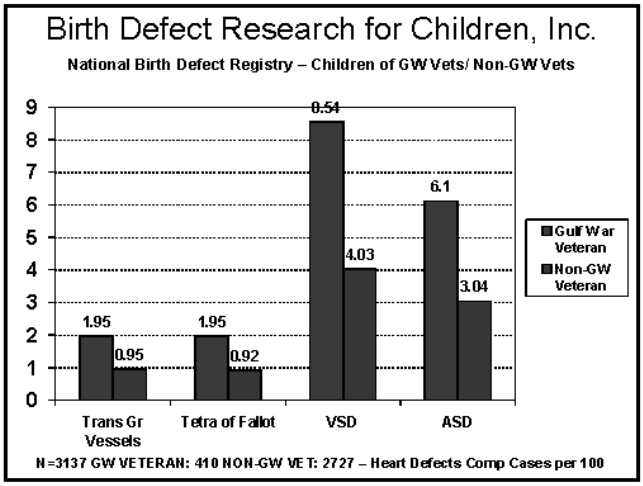
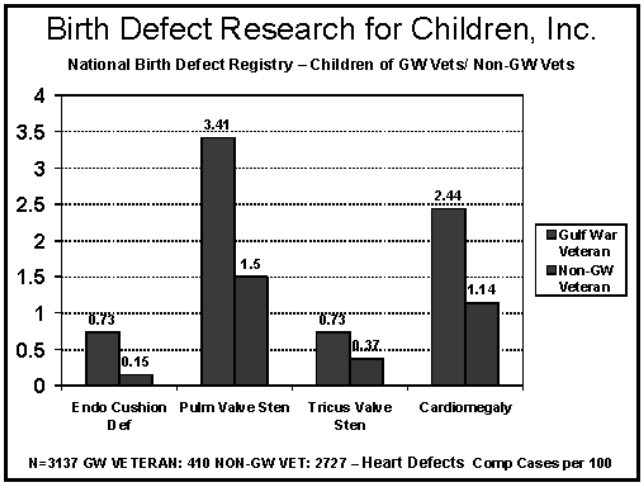
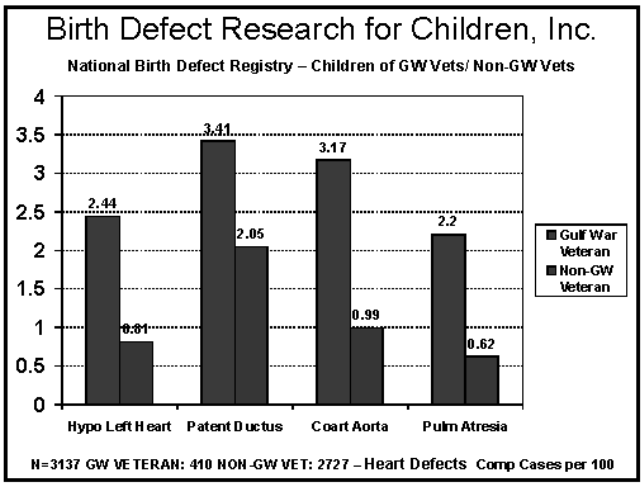
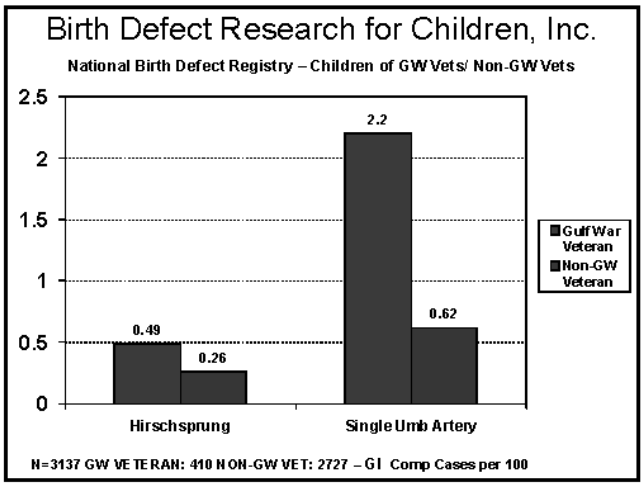
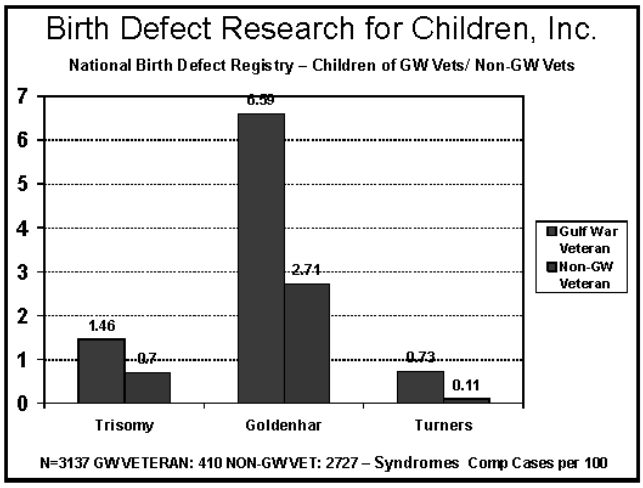
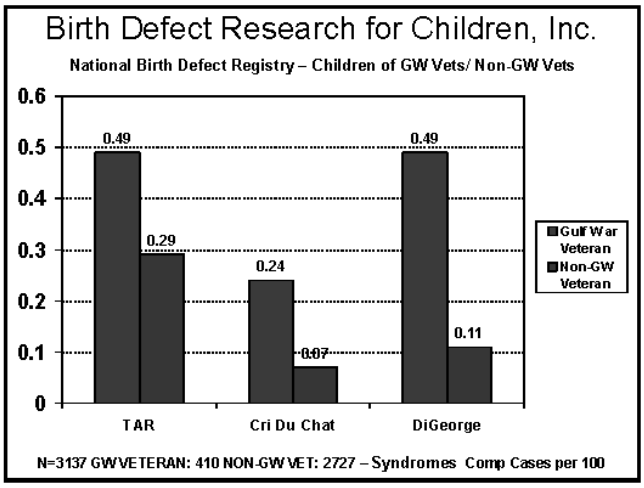

Birth Defect Research for Children, Inc.
National Birth Defect Registry – Children of GW Vets/ Non-GW Vets
9
8
7
6
5
4
3
2
1
0
1.95
0.95
1.95
0.92
8.54
4.03
6.1
3.04
Trans Gr Vessels
Tetra of Fallot
VSD
ASD
Gulf War Veteran
Non-GW Veteran
N=3137 GW VETERAN: 410 NON-GW VET: 2727 – Heart Defects Comp Cases per 100

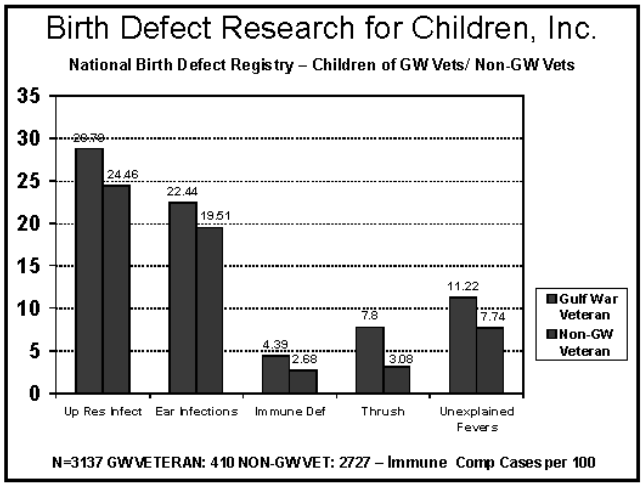

Birth Defect Research for Children, Inc.
National Birth Defect Registry – Children of GW Vets/ Non-GW Vets
4
3.5
3
2.5
2
1.5
1
0.5
0
0.73
0.15
3.41
1.5
0.73
0.37
2.44
1.14
Endo Cushion Def
Pulm Valve Sten
Tricus Valve Sten
Cardiomegaly
Gulf War Veteran
Non-GW Veteran
N=3137 GW VETERAN: 410 NON-GW VET: 2727 – Heart Defects Comp Cases per 100


Birth Defect Research for Children, Inc.
National Birth Defect Registry – Children of GW Vets/ Non-GW Vets
4
3.5
3
2.5
2
1.5
1
0.5
0
2.44
0.81
3.41
2.05
3.17
0.99
2.2
0.62
Hypo Left Heart
Patent Ductus
Coart Aorta
Pulm Atresia
Gulf War Veteran
Non-GW Veteran
N=3137 GW VETERAN: 410 NON-GW VET: 2727 – Heart Defects Comp Cases per 100


Birth Defect Research for Children, Inc.
National Birth Defect Registry – Children of GW Vets/ Non-GW Vets
2.5
2
1.5
1
0.5
0
0.49
0.26
2.2
0.62
Hirschsprung
Single Umb Artery
Gulf War Veteran
Non-GW Veteran
N=3137 GW VETERAN: 410 NON-GW VET: 2727 – GI Comp Cases per 100







Goldenhar Syndrome

- Incidence ranges from 1/14,699 to 1/45,000 births
- Associated with teratogens
  - Thalidomide
  - Primidone
  - Accutane
- Some cases familial
- Others "phenocopies"
- Aranetta study found tripling of Goldenhar in GW children born in military hospitals

Goldenhar Case Study

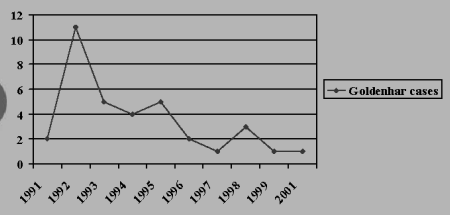
- 24 Goldenhar – fathers deployed
- 7 Goldenhar critera fathers deployed
- 2 Goldenhar fathers in Gulf after war
- 33 Goldenhar associated with Gulf service

Goldenhar Case Study

7 Goldenhar fathers non-deployed

23344	Steel worker
22970	Shots/solvents
26815	Cont gear
26896	Shots/Naptha
30868	Shots/lead fuel
45947	mechanic
48695	Cont gear

Goldenhar Case Study
DOB Distribution



Goldenhar Case Rates

- 16 D Goldenhar DOB prior 10/1/93
- 3 ND Goldenhar DOB prior 10/1/93
- 56,782 births to deployed vets*
- 68,908 births to non-deployed vets*

Crude rates for Goldenhar:
Deployed – 28 per 100,000
Non-deployed – 4 per 100,000

*Araneta, Teratology, 1997.

Goldenhar Details

- Medical records confirmation 14/19
- 9/16 healthy children before GW
- 2/16 healthy children after birth of child with Goldenhar Syndrome
- 16/16 Goldenhar first born after GW