



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

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

# BIRTH DEFECT AND DISABILITIES REGISTRY QUESTIONNAIRE

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

Date:     /    /     Reporting person's name: \_\_\_\_\_  
Mo Day Yr

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: <input type="radio"/> Male <input type="radio"/> Female	Blood Type: <input type="radio"/> O <input type="radio"/> A <input type="radio"/> B	AB <input type="radio"/> AB RH+ <input type="radio"/> RH+ RH- <input type="radio"/> RH-	Race: <input type="radio"/> Asian or Pacific Islander <input type="radio"/> Black (non-Hispanic) <input type="radio"/> Hispanic	<input type="radio"/> Native American or Alaskan Native <input type="radio"/> White (non-Hispanic) <input type="radio"/> Other (please specify): _____
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Date of birth:     /    /     Place of birth: \_\_\_\_\_  
Mo Day Yr 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  yes  no  don't know  
 do not have birth defects? \*Do not include children from other marriages.

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

DOB:     /    /      Male  Female  
Mo Day Yr

DOB:     /    /      Male  Female  
Mo Day Yr

DOB:     /    /      Male  Female  
Mo Day Yr

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     /    /      
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.**

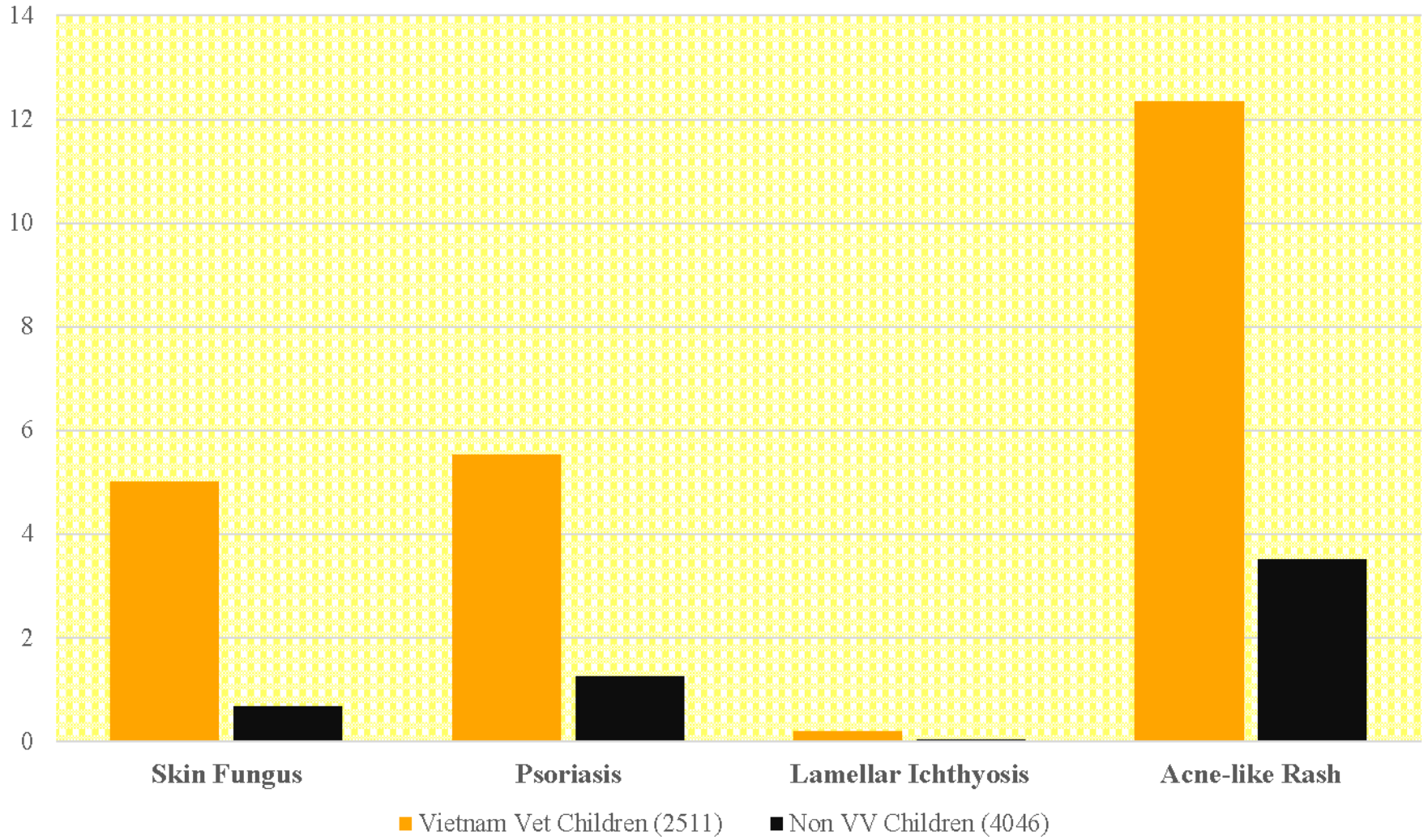
### Central Nervous System (CNS)

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

# Agent Orange

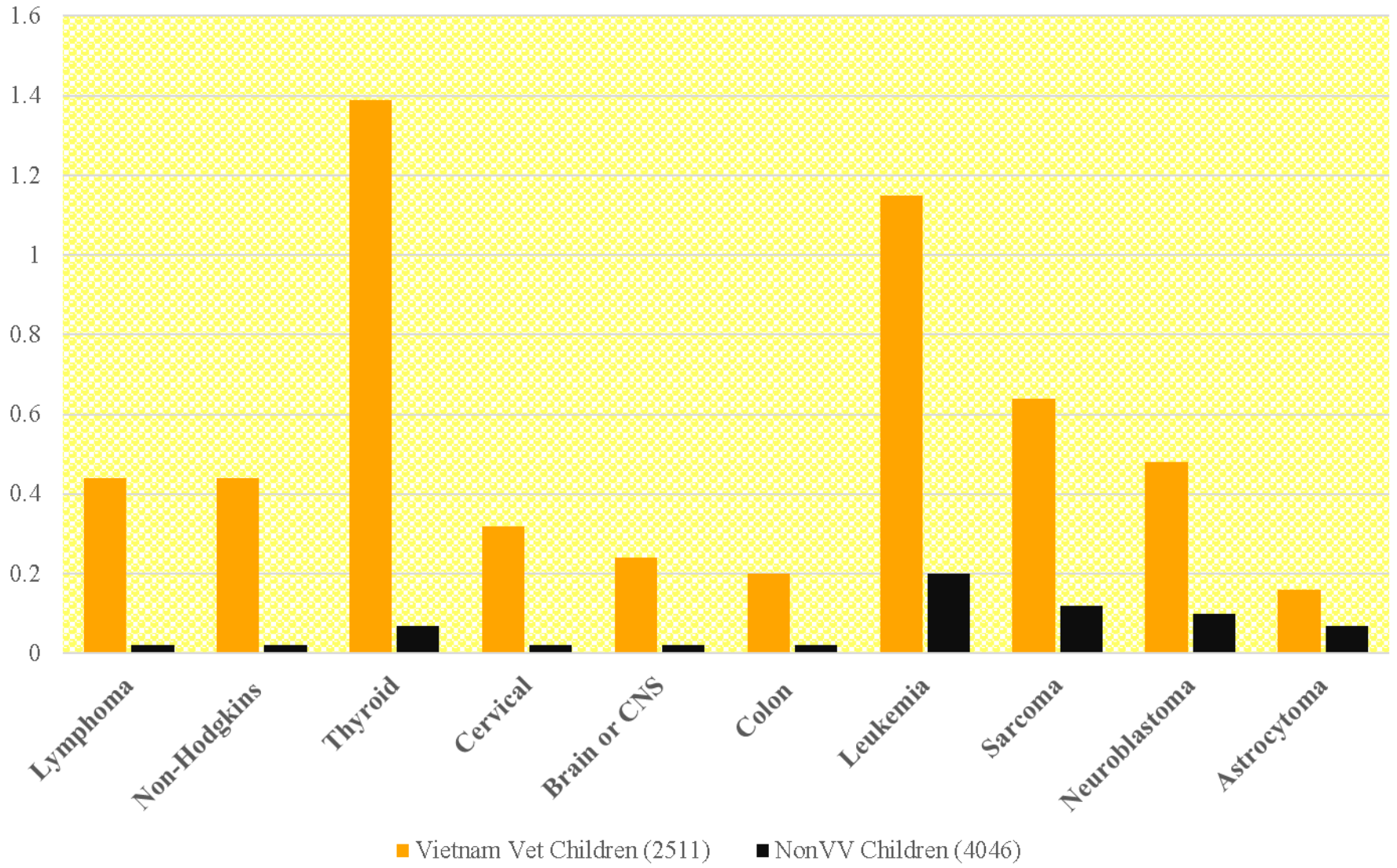
- 2-45T/2-4D/TCDD
- TCDD targets immune system
- Ectodermal effects
- Neurobehavioral effects
- Thyroid defects
- Abnormalities of teeth
- Alterations in learning

# Skin Defects

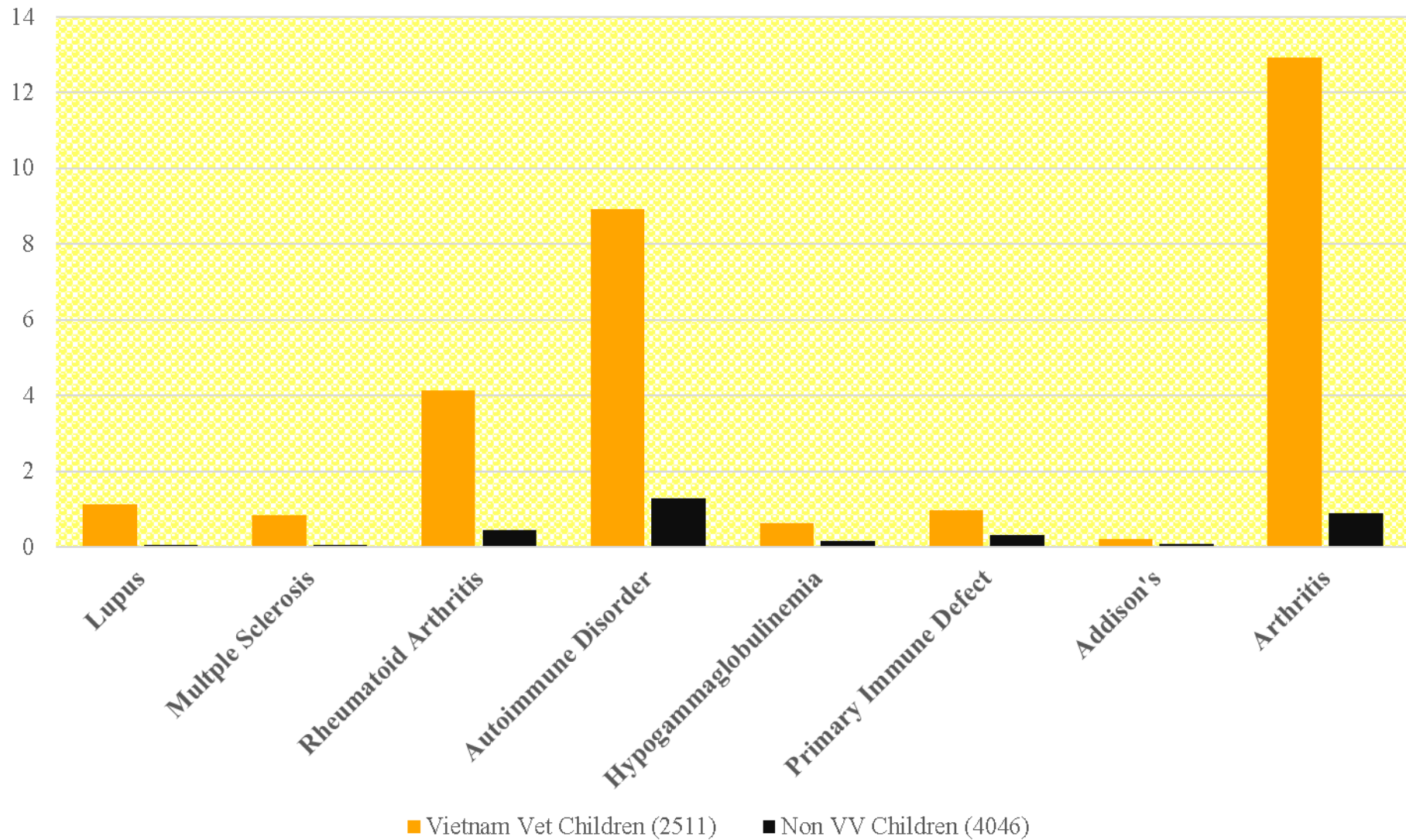




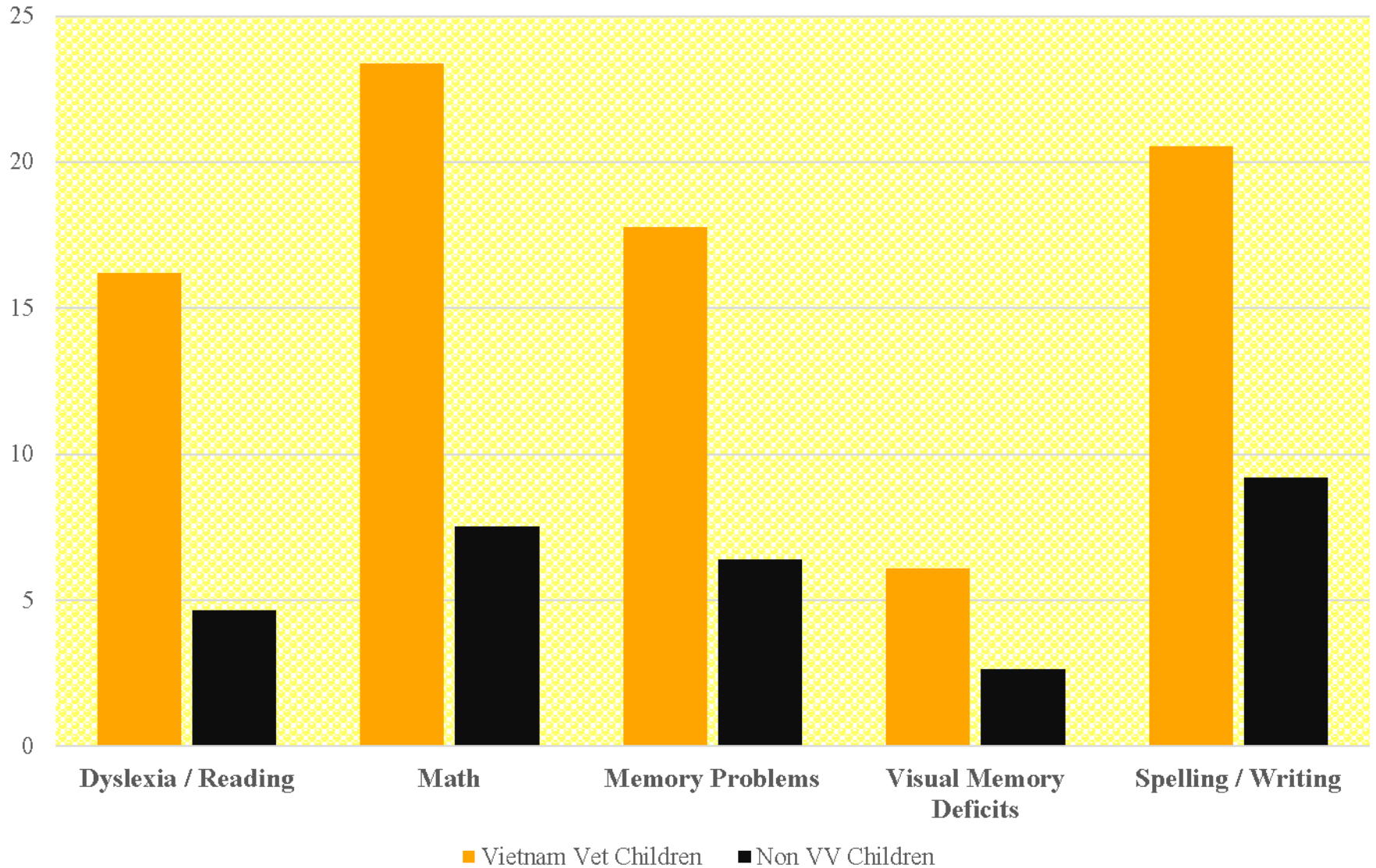
# Cancer



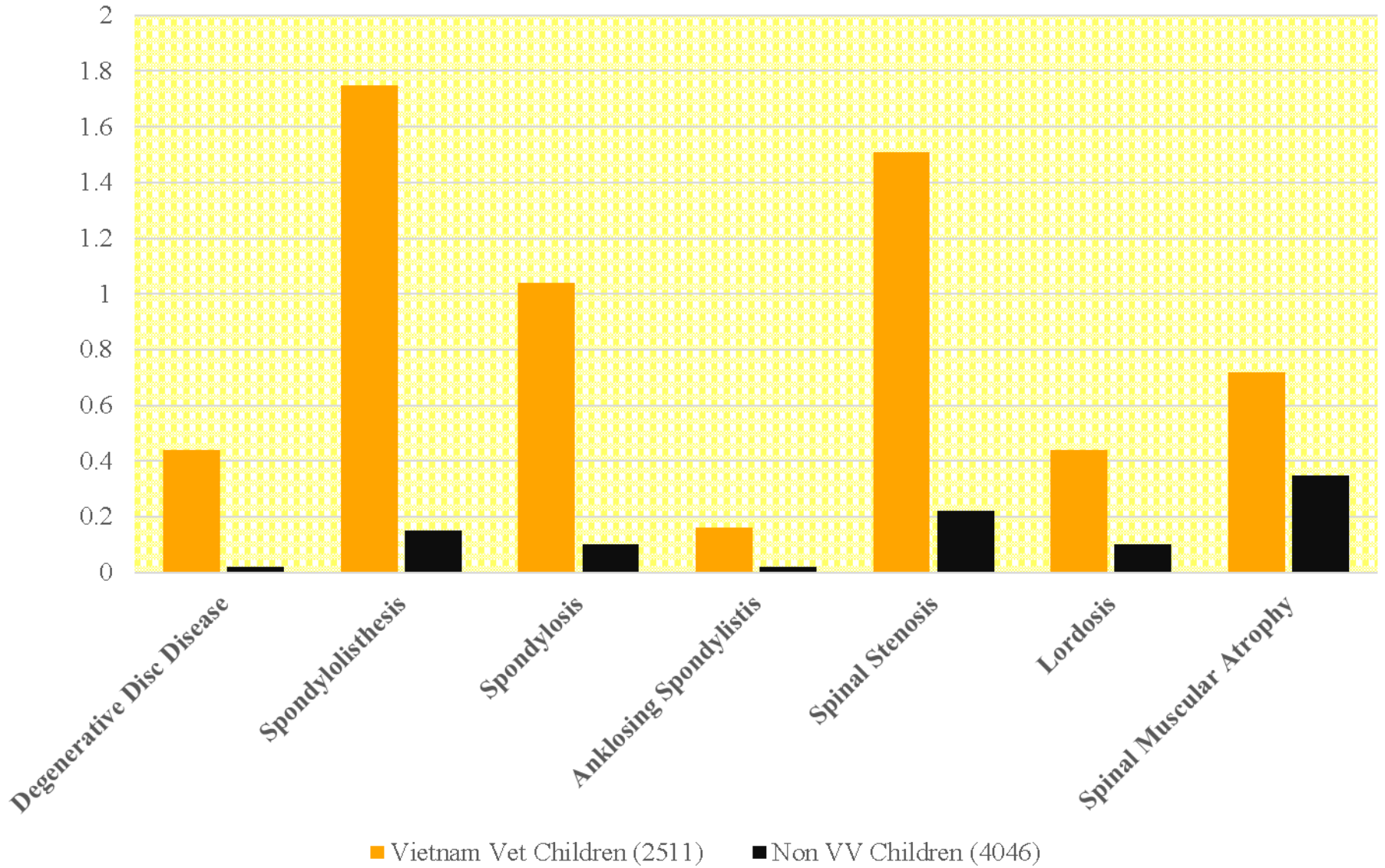
# Immune Response Disorder



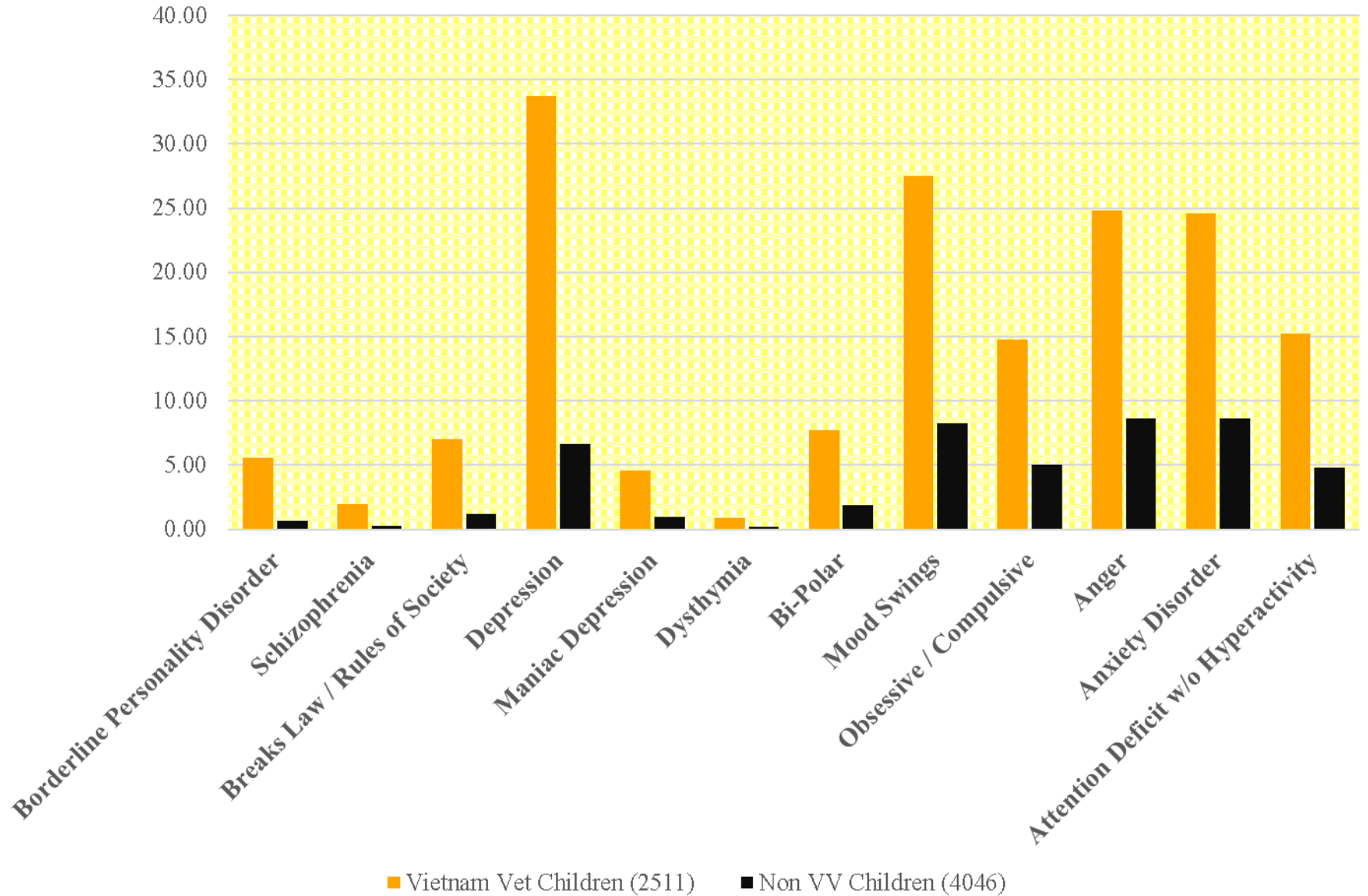
# Learning Disabilities



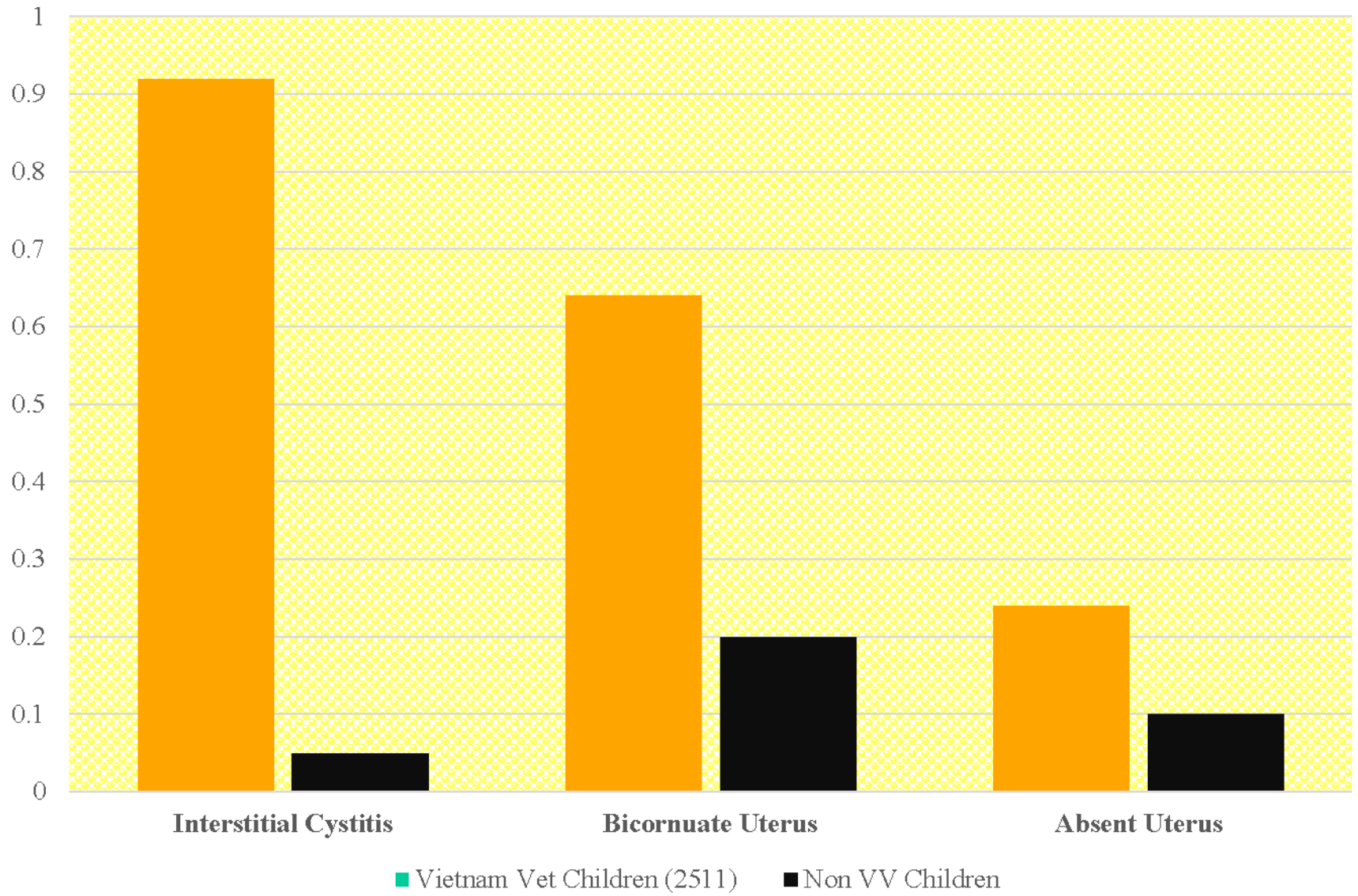
# Spine Defects



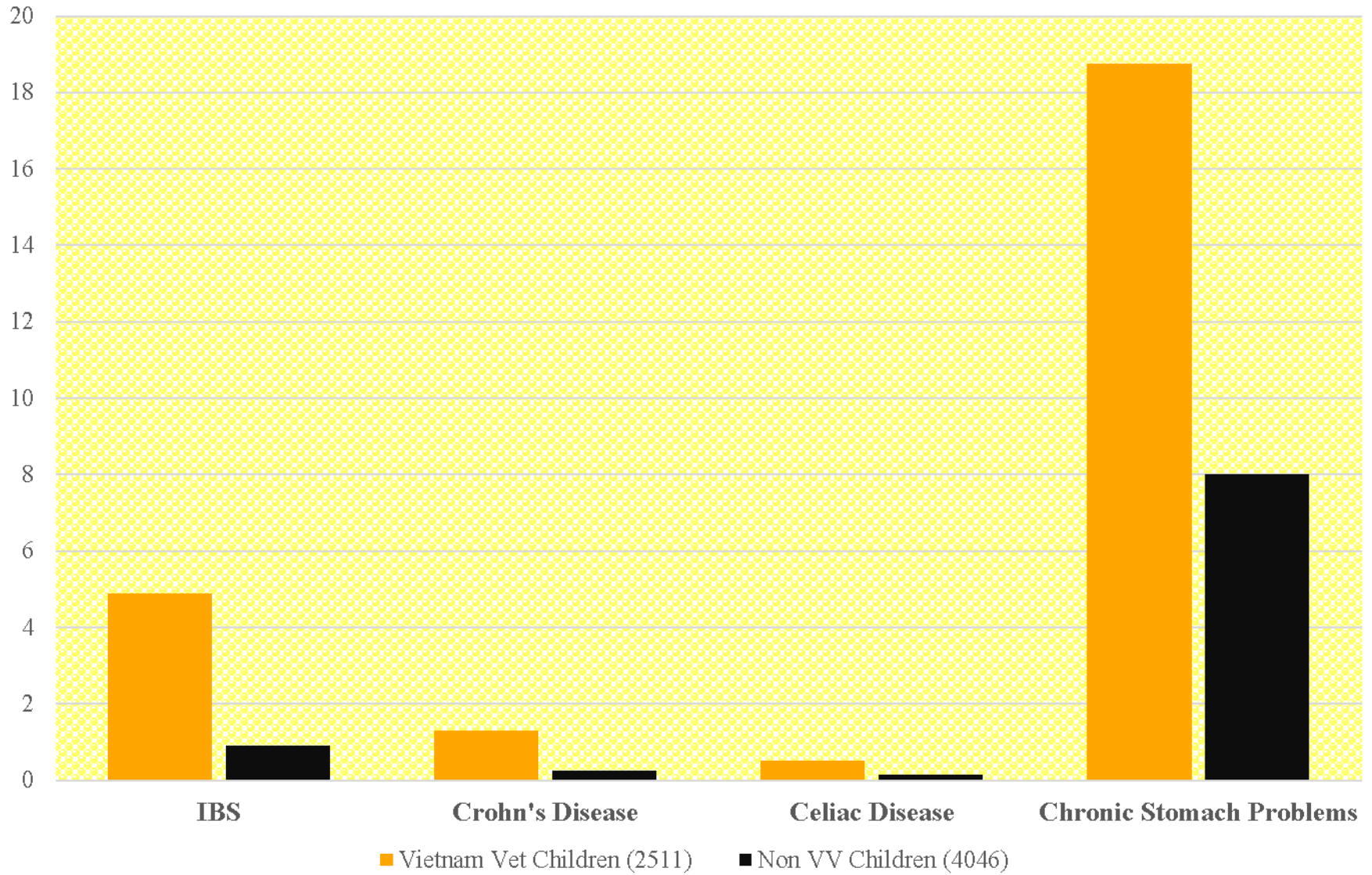
# Emotional / Behavioral



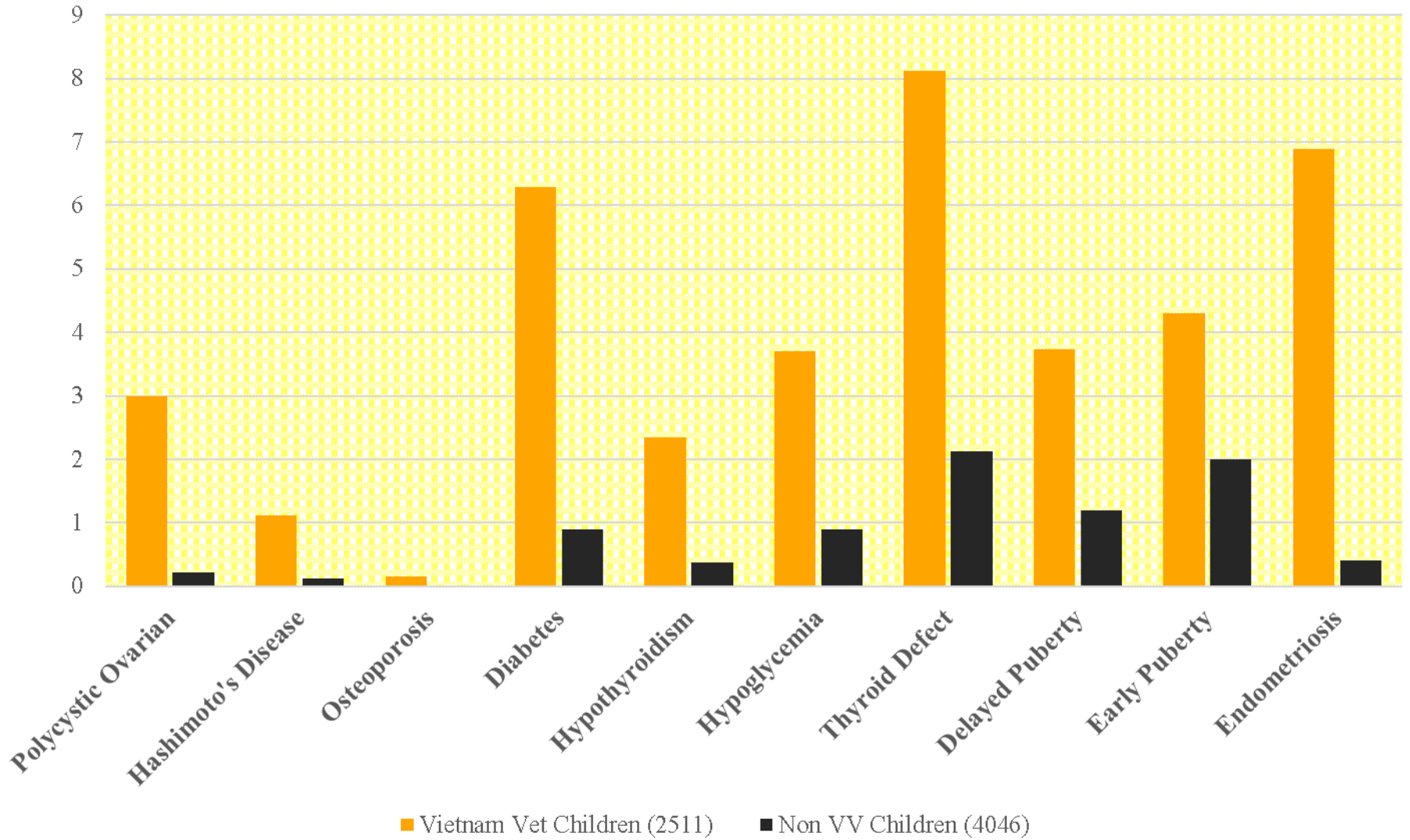
# Genitourinary Defects



# Gastrointestinal Defects

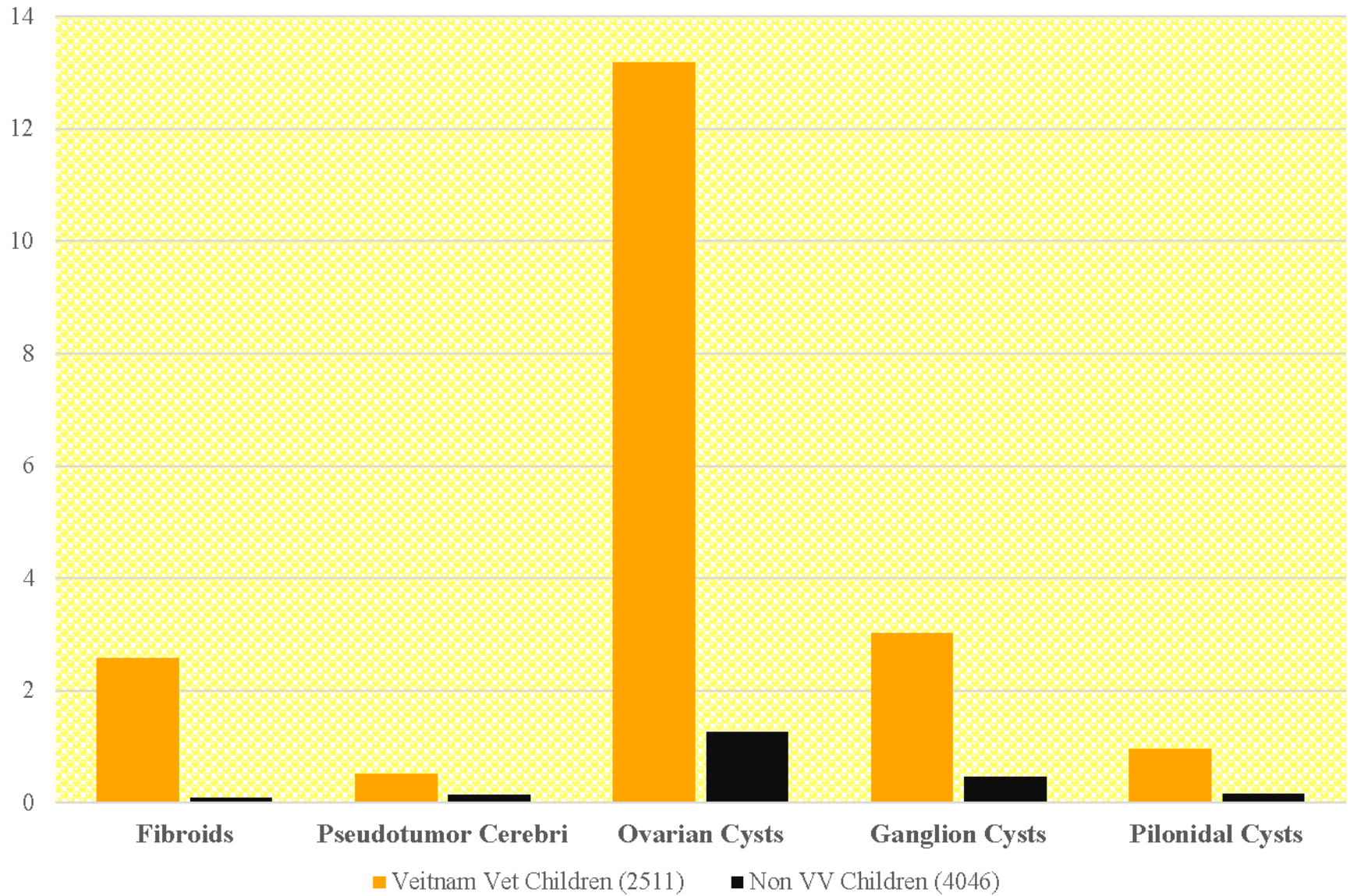


# Endocrine Defects

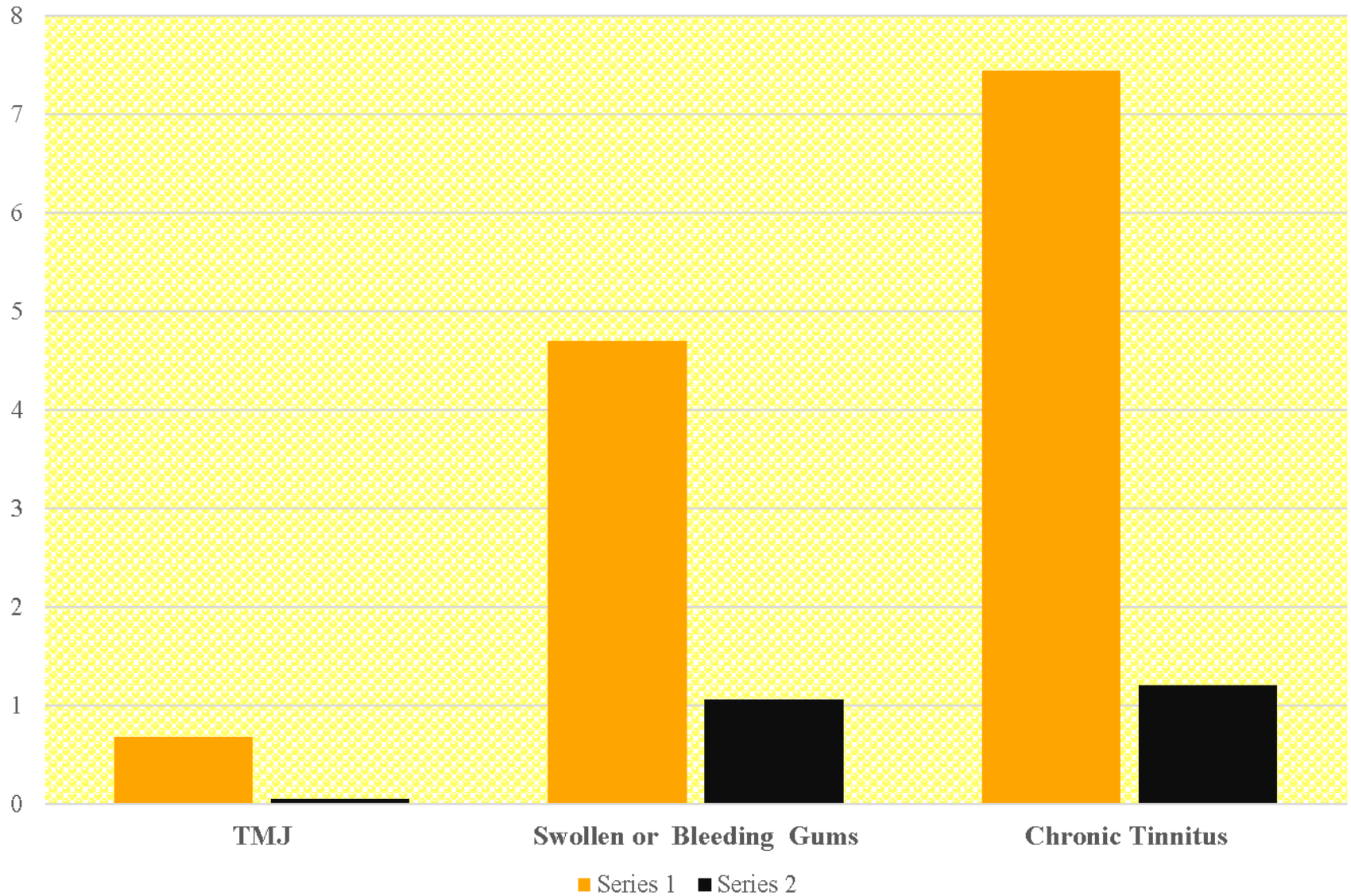




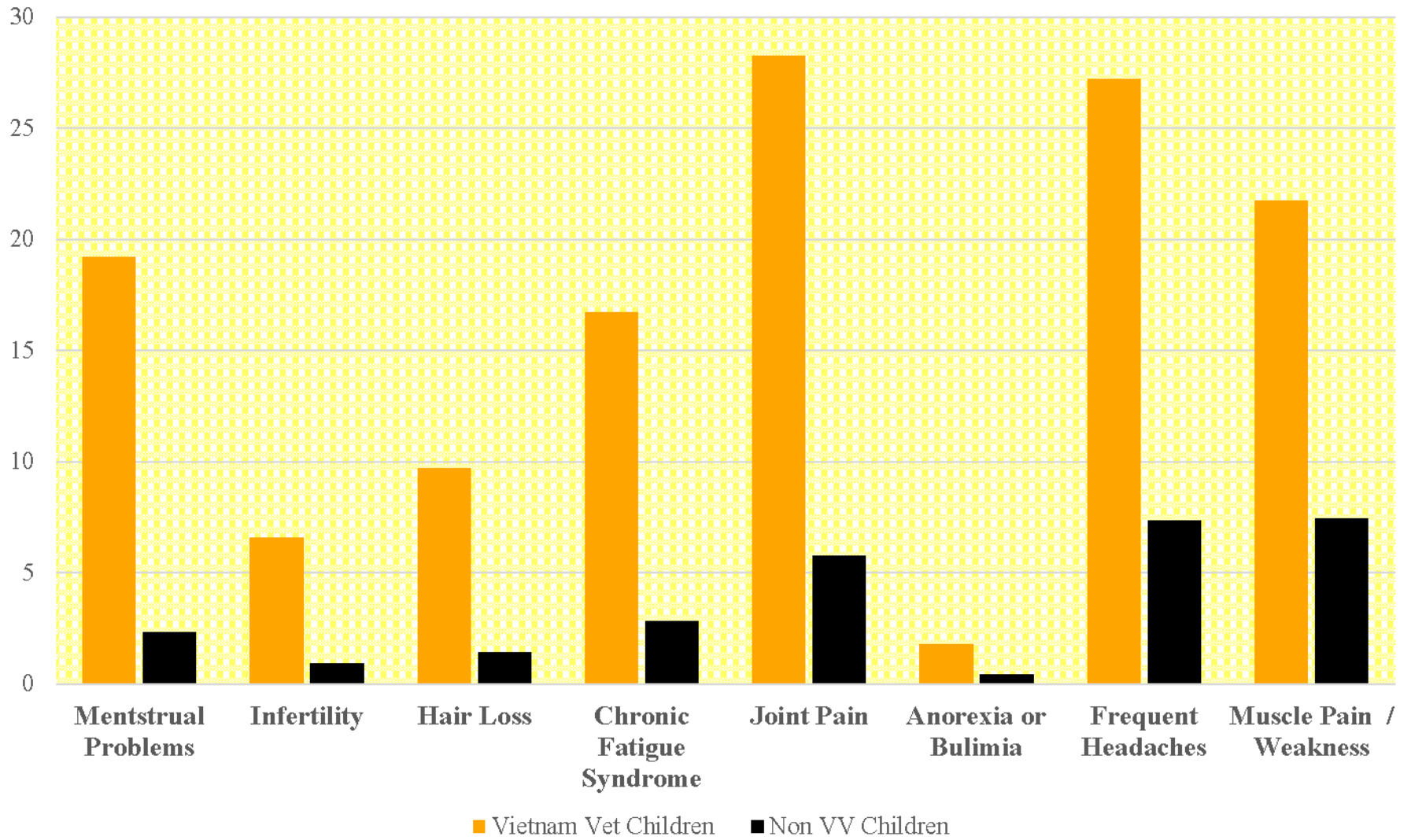
## Tumors (Benign) and Cysts



# Craniofacial and Ear Defects



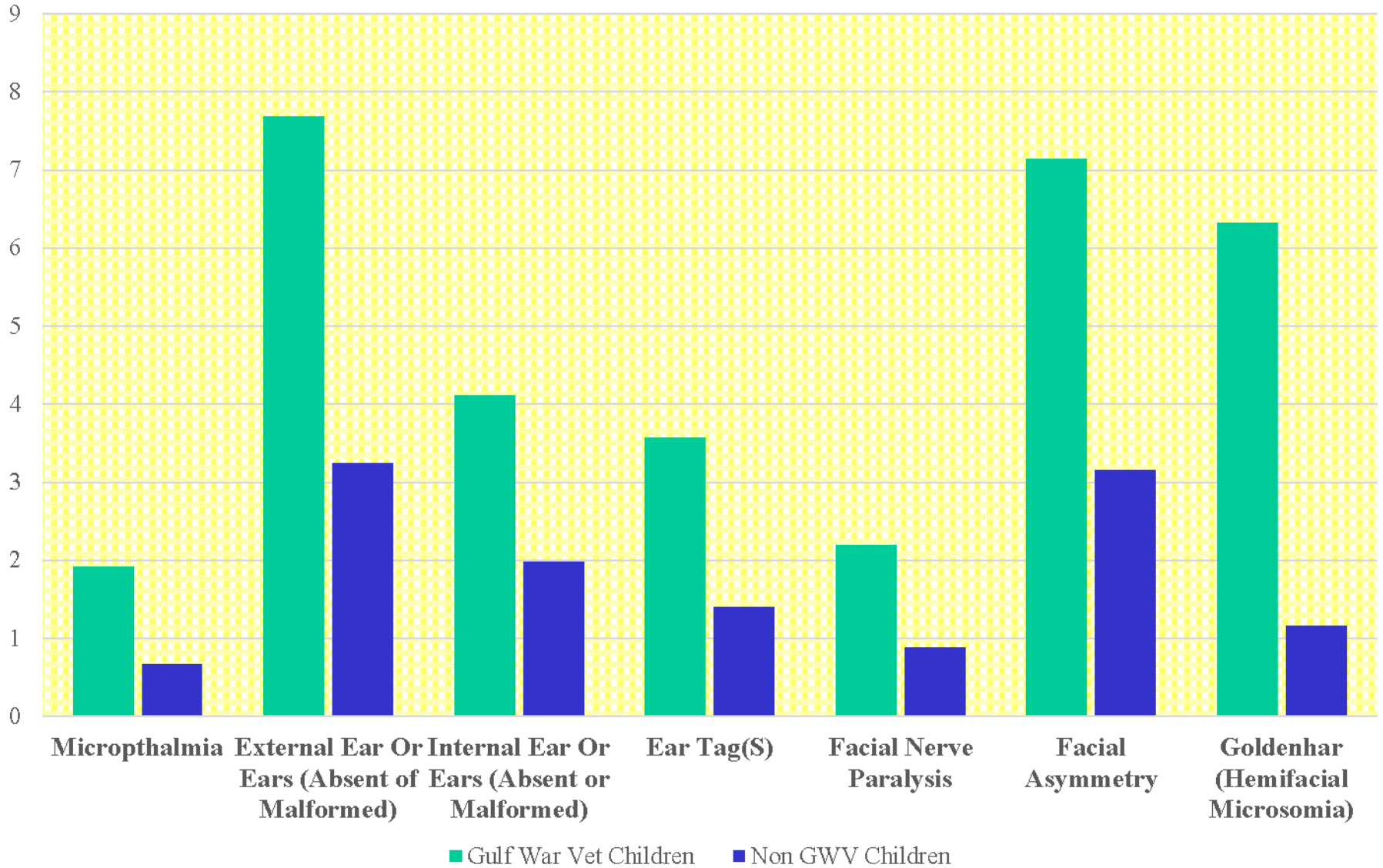
## Misc Defects



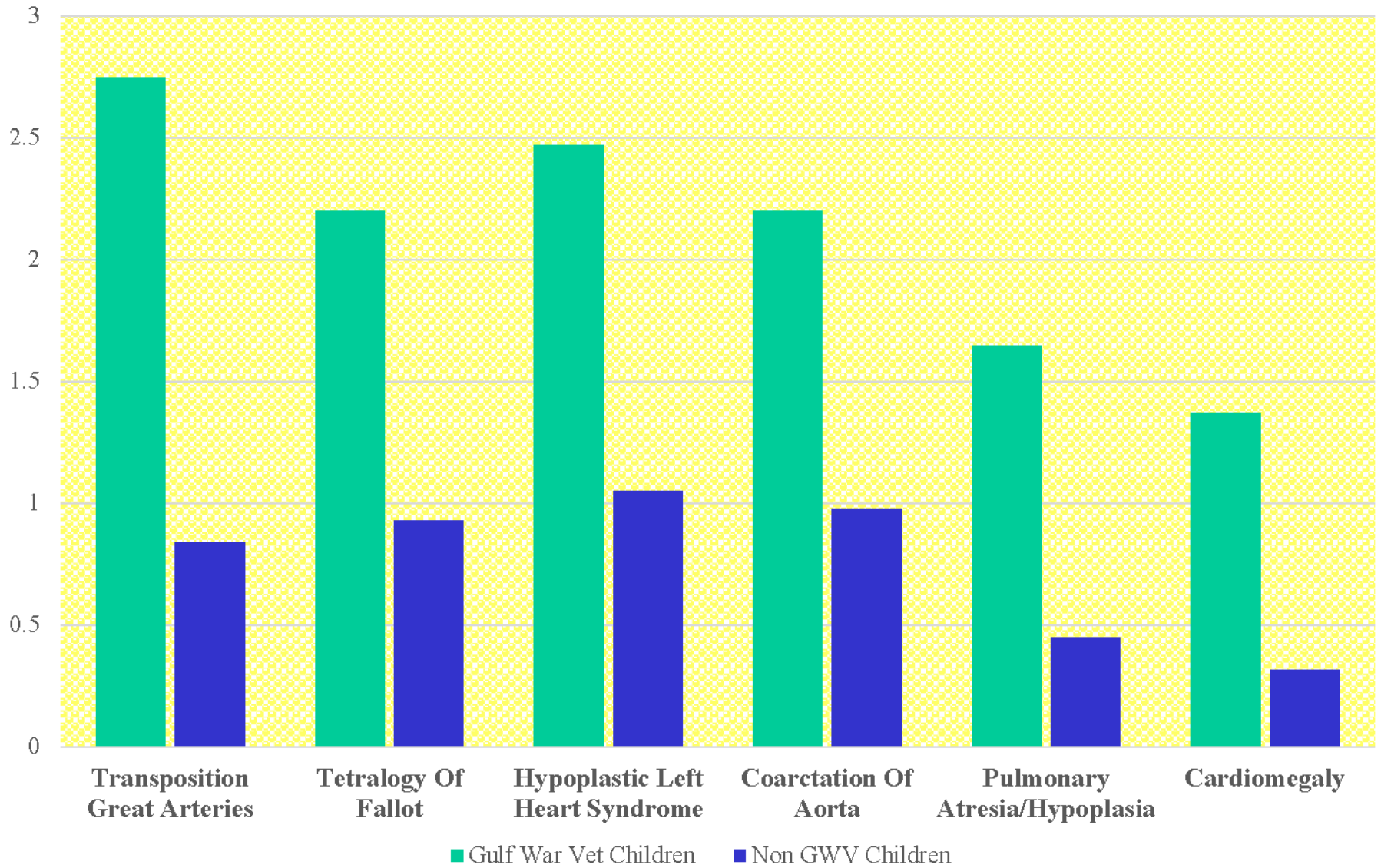
# Gulf War Exposures

- 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

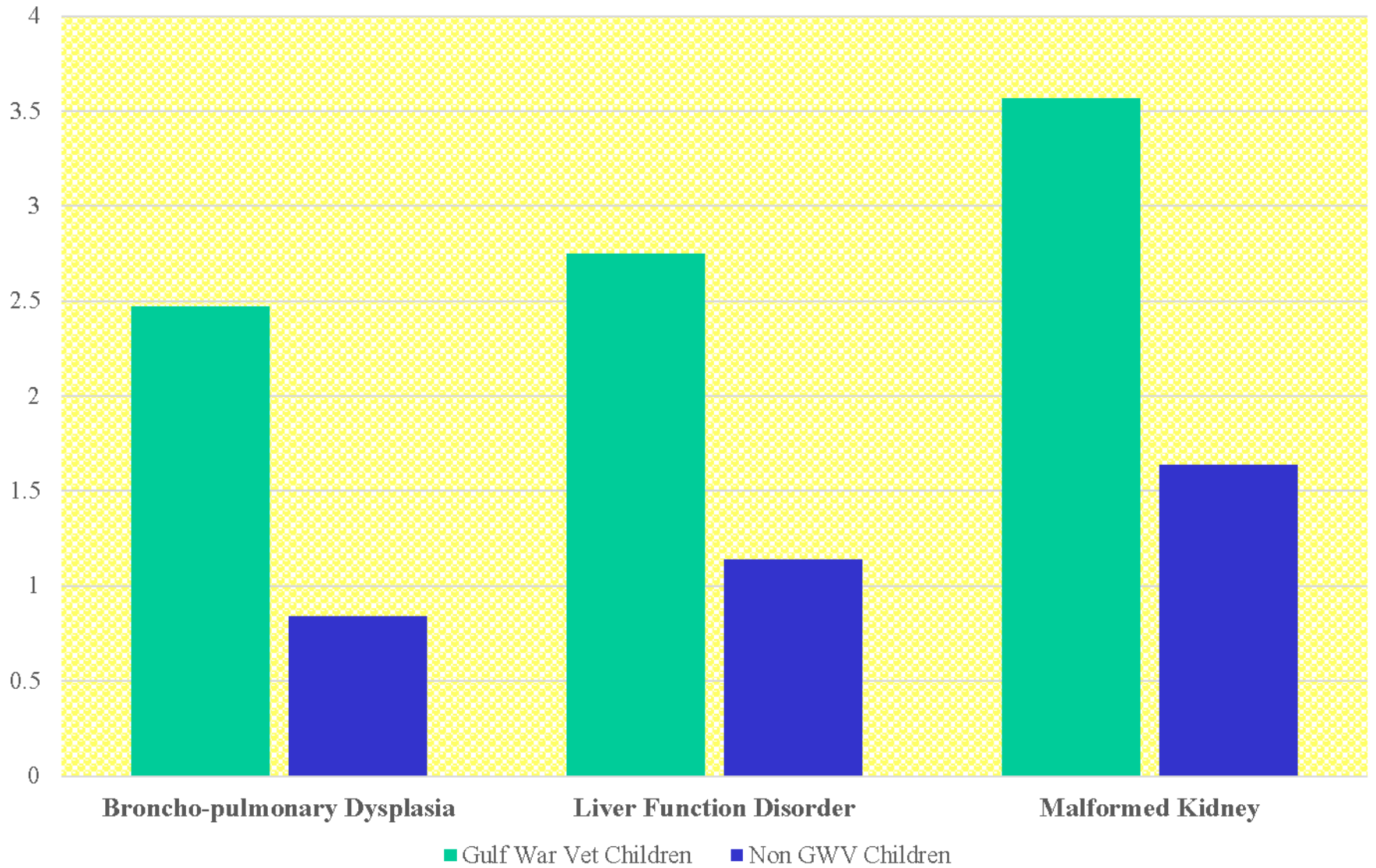
# Craniofacial Defects



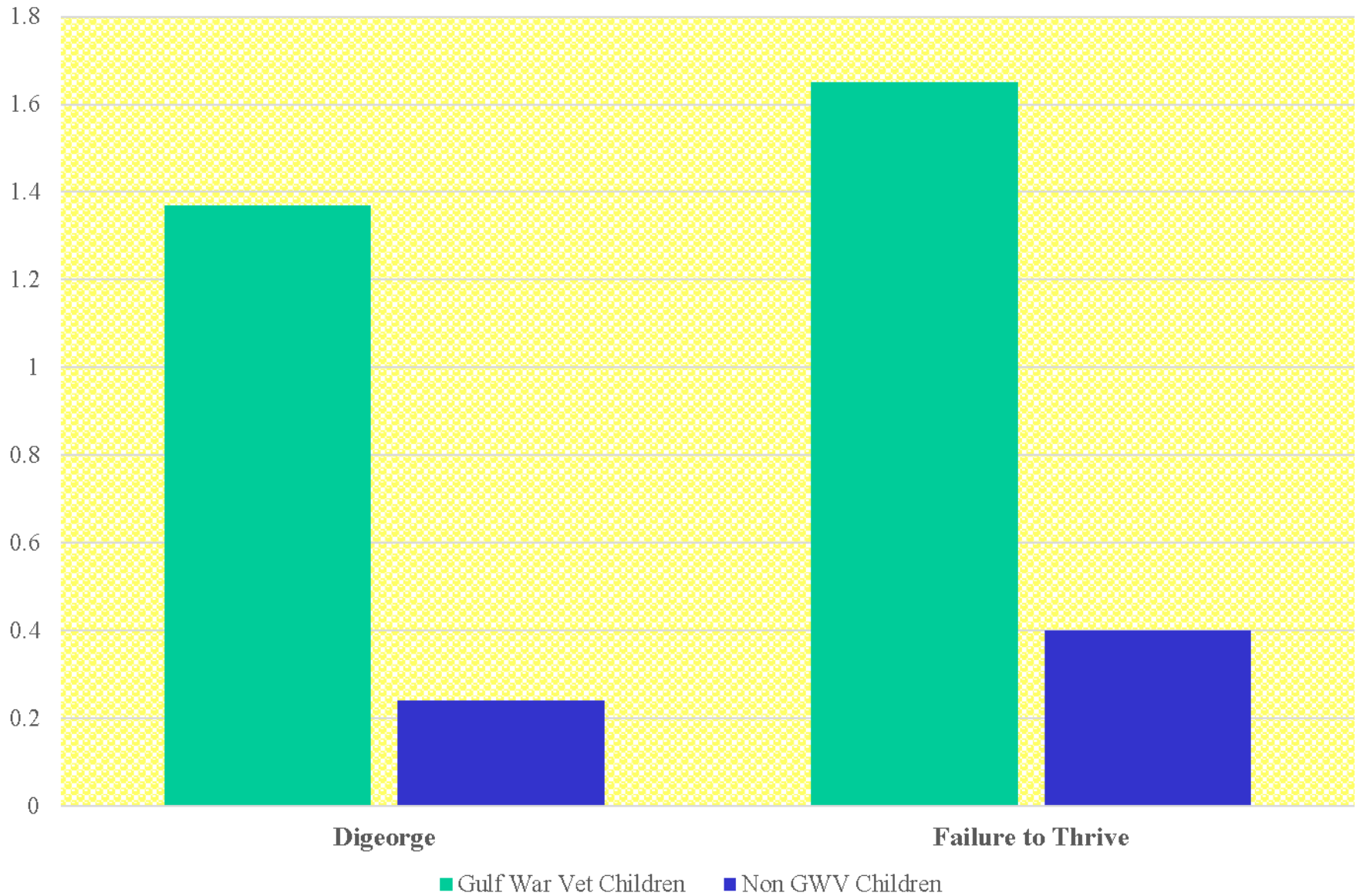
# Heart Defects



# Liver Lung Kidney Defects



# Misc Defects





# 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”