

.Approved: 4-26-96  
Date

MINUTES OF THE SENATE COMMITTEE ON FEDERAL AND STATE AFFAIRS.

The meeting was called to order by Senator Lana Oleen at 11:15 a.m. on March 21, 1996 in Room 254-E of the Capitol.

Members present were: Senator Oleen, Chair  
Senator Tillotson, Vice Chair  
Senator Jones, Ranking Minority Member  
Senator Jordan  
Senator Hensley  
Senator Papay  
Senator Praeger  
Senator Walker

Members not present: Senator Gooch - excused  
Senator Ramirez - excused  
Senator Vidricksen - excused

Committee staff present: Mary Galligan, Legislative Research  
Nancy Wolff, Committee Secretary

Conferees appearing before the committee:  
Representative Thimesch  
Jim Bunker, DAV Commission  
Leslea Mosher Jones, a Topeka resident

A hearing was scheduled for SCR5046, Gulf War illness, memorialize Congress to take action and HCR5047, Gulf War illness registry. Representative Thimesch, of Cheney, presented a film entitled The Gulf War + 5 that was presented on 60 Minutes and narrated by Dan Rather. He also handed out testimony with regard to Gulf War Syndrome and information on what other states are doing to support those veterans who are afflicted with the Syndrome (Attachment 1 and Attachment 2).

Senator Jones requested what the purpose of the registry was and if it was to determine scientifically whether the child or the parent has a problem, then it had to be passed on through the seed of the father. Jim Bunker of the DAV Commission, stated that the registry is something that is fairly simple. He stated that when he returned from the Gulf War and was hospitalized at the Veterans' Hospital, the registry was maintained on a 3" x 5" card. When he returned to the hospital one year later, the hospital was unable to find his card and he was asked to fill out a new form which was a 26-page form of questions to answer.

Leslea Mosher Jones, a Topeka resident, distributed a hand-out to the committee in support of HCR5046 and HCR5047 (Attachment 3).

Senator Hensley made a motion that HCR5046 be reported favorable for passage and Senator Jordan seconded the motion. The motion carried.

Senator Oleen stated that there were more questions to be answered on HCR5047 before the committee could make an educated decision, so the issue would be taken up before the end of the current legislative session.

The meeting was adjourned at 11:40 a.m.

DAN THIMESCH  
 REPRESENTATIVE, 93RD DISTRICT  
 30121 WEST 83RD STREET SOUTH  
 CHENEY, KANSAS 67025  
 (316) 531-2995

STATE CAPITOL  
 ROOM 278-W  
 TOPEKA, KANSAS 66612-1504  
 (913) 296-7680  
 1-800-432-3924  
 (DURING SESSION)



TOPEKA

HOUSE OF  
 REPRESENTATIVES

COMMITTEE ASSIGNMENTS

EDUCATION  
 LOCAL GOVERNMENT

## PURPOSE OF RESOLUTION TO FEDERAL GOVERNMENT

5046

When our government sends men and women across the seas and places them in harm's way, the least they can expect is honest disclosure of the facts and prompt and effective medical care for those who suffer wounds or illness from performing their duties. Such does not appear to be the case regarding Gulf War veterans.

Written reports suggest the strong possibility that a number of United States military personnel were exposed to chemical or biological agents during the war. To date the federal government denies this. During a Congressional hearing held in Washington, D.C., on March 9, 1995 an American Legion spokesman made the following comment:

"Mr. Chairman, when veterans and their families first began to report their health problems, VA (Veterans Administration) and DoD (Department of Defense) tried to deny that Persian Gulf veterans were ill. Then veterans were told their medical problems were all due to stress. Recently, veterans were told 'we know you are sick, we don't know what you have, but you did not get it in the Persian Gulf.' Now the explanation is 'we know you are sick, here is what you have and you would have gotten this whether or not you went to the Persian Gulf.' The facts still remain that healthy men and women deployed to the Persian Gulf War and since their return, their health has deteriorated. Whether veterans incurred injury or aggravated an existing condition, this nation has an obligation to make them 'whole.'"

Documentaries on topic presented by:

60 Minutes - Dan Rather  
 CNN  
 Donahue  
 Arts and Entertainment Channel

*Dan Thimesch*

*Federal and State Affairs*  
*3/21/96*  
*Attachment 1*

## STATE BILLS AND RESOLUTIONS

### Massachusetts Senate Bill 1993 - (in committee- may move any day)

Would set up a commission to study the effect of the "Gulf War Syndrome" and the impact in the State.

### Ohio HB 117 - (Signed 6/30/95)

Appropriate \$100,000 in fiscal year 1996, a comprehensive research study to determine the medical effects as well as employment, social, emotional and family problems that have been incurred.

### Pennsylvania House Resolution No. 241 - (adopted)

Memorializing Congress to investigate mysterious medical symptoms of Veterans of Operation Desert Storm.

### California Senate Joint Resolution 19 - (adopted)

A petition to expedite research and dollars to solve the problem.

### Colorado Senate Joint Resolution 95-27 - (adopted 5/4/95)

Urging additional Federal action to diagnose and treat any serious illnesses of Veterans of the Persian Gulf Hostilities. Asking to declassify information that could possibly have any bearing on illness. Investigate the communicability, access government documents regarding environmental exposure to chemical and biological warfare agents, place a moratorium on donation of blood, blood products, and organs by veterans.

### Illinois HB 1760 - (in committee)

Changing their Department of Veterans Affairs by amending Section 2 - duties and powers. Obtaining any advantage, benefit, assistance, services and resources for veterans and their dependents. Create a program that State veteran facilities could treat veterans.

The Department could accept and hold on behalf of the State, a grant, gift, devise, or bequest of money or property for the general benefit of Illinois veterans. To be kept as a distinct fund.

### Town resolution Santa Cruz New Mexico (Passed 10/27/94)

Urging a ban on blood and tissue donated by Persian Gulf War Veterans until doctors investigate the veterans' theories about virus or bacteria.

DAN THIMESCH  
 REPRESENTATIVE, 93RD DISTRICT  
 30121 WEST 63RD STREET SOUTH  
 CHENEY, KANSAS 67025  
 (316) 531-2995



COMMITTEE ASSIGNMENTS

EDUCATION  
 LOCAL GOVERNMENT

STATE CAPITOL  
 ROOM 278-W  
 TOPEKA, KANSAS 66612-1504  
 (913) 296-7680  
 1-800-432-3924  
 (DURING SESSION)

TOPEKA  
 HOUSE OF  
 REPRESENTATIVES

HCR5047

Many Veterans believe that they were exposed to different hazards of war. Exposure to smoke from oil well fires, depleted uranium, infectious biological weapons, and injection of unknown drugs into their systems. They came home and didn't feel right. Muscle aches, joint aches, a shortness of breath, etc. Many of them believe they have passed serious health problems on to their spouses and children. Government studies show no higher rate of birth defects in children of Gulf War Veterans. One association says its finding more children of Gulf War Veterans with deformities.

*of Resolutions*  
 PURPOSE: ~~To bring about a Registry.~~

To identify those spouses and children of Veterans, and others in Kansas that have symptoms or illnesses of the Persian Gulf War.

The medical experts argue about the "Gulf War System Facts" and keep very busy throwing "rocks" at each other. There appears to be no effort to even work together. More and more people feel abandoned and they are angry about this lack of cooperation.

I believe it is time for all of us in leadership positions to work together to answer some of these concerns. I hope you will help me and others to put together a system that at least will identify these people and where they live. We need them to be on a data collection base so that we can truly understand the magnitude of this problem in Kansas.

Most importantly, in the event that a procedure or treatment is found to have a good effect on this illness, we could communicate and spread this information to those most in need.

I urge each one of you to do your part in making this happen.

God be with us.

*Dan Thimesch*  
 Senate Federal, State Affairs  
 3/21/96  
 Attachment 2

# Keeping her ears open

## CDS assistant prof searches for evidence of Gulf War syndrome in Wichita area vets

By Kathy Holm

Gulf War syndrome has puzzled medical experts since the Persian Gulf War ended in 1991.

### DISCOVERIES

Some U.S. soldiers who served in that war came home complaining of a variety of symptoms — dizziness, nausea, loss of feeling in their arms, and headaches — that have not yet been recognized as a disease.

Aukse Bankaitis, assistant professor in communicative disorders and sciences at WSU, has just received a WSU research/creative projects award to look at Gulf War syndrome and detect if some Wichita veterans have suffered neurological damage during their tours of duty. Her study is titled: "Gulf War Syndrome and the Auditory Brainstem Response: A Pilot Study."

One of Bankaitis' graduate students knows some Gulf War veterans at McConnell Air Force Base and became interested in the subject, she said. "We began brainstorming about how to detect damage veterans may have suffered and came up with the idea to look at auditory brainstem response," she said.

An ABR test is a hearing test normally used to detect tumors and other problems on the auditory nerve. The subject sits in a chair, wears a headset and receives a delayed series of clicks into the ear. Electrodes are placed on the head and shoulder to record the subject's brain wave patterns.

"This test is objective and very

sensitive in detecting any neurological damage or problems," Bankaitis said. "If there's anything there, this test will detect it."

Bankaitis and two CDS second-year audiology graduate students, Kurt Smith and Candace McGhee, will perform the test on three groups of 10-15 subjects from McConnell and the 1st/137th Infantry Armed Guard in Wichita.

Because there are detectable gender differences in ABR, either male or female subjects had to be chosen, Bankaitis said. All of the subjects are male in this study.

The first group will be men who suffer from Gulf War syndrome symptoms. The second group will be males who served in the war but have not suffered symptoms. The third group will be men in the armed services who have never served in the Persian Gulf.

"We're not looking for a cause of the syndrome with these tests," Bankaitis said. "If we are able to detect neurological problems and get this recognized as a disease, however, other researchers can pick up where we left off to pinpoint the cause or causes and work to find a cure."

Bankaitis said they expect tentative results in May or June.

Although his work is not included as part of the grant, Brian Stone, assistant professor in administration, counseling, educational and school psychology, is administering a series of memory tests to look at the neuropsychological functioning of Gulf War vets.

"The tests we've selected to give are the kinds of tests typically involved when there is neurological dysfunction; hopefully we'll find something," he said.

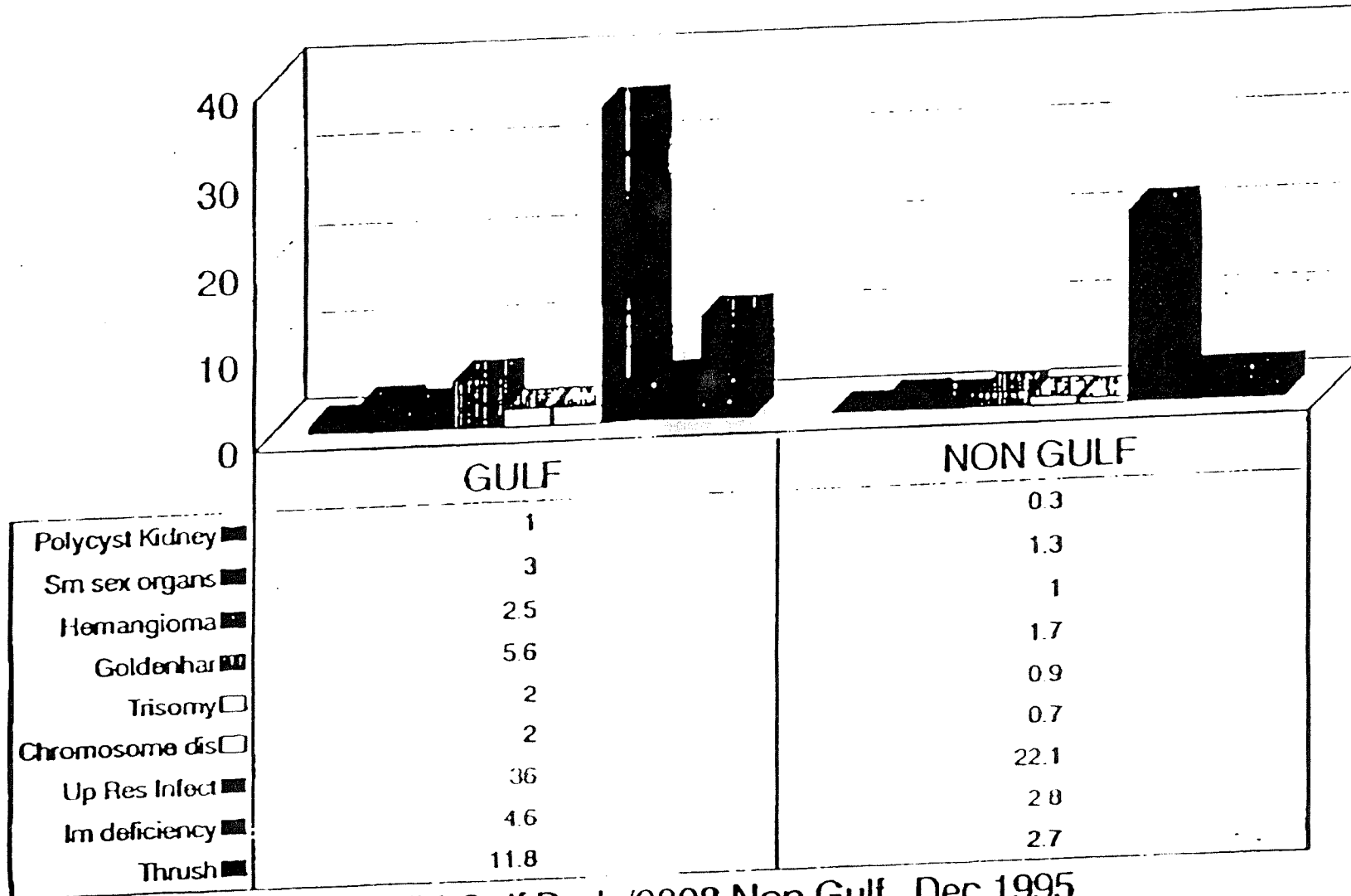


David Dinell

Aukse Bankaitis, left, demonstrates how the study is done with Persian Gulf War veterans, assisted by Gary Topping, instructor and clinical supervisor, and Melinda Switzer, a graduate student in audiology.

# ASSOCIATION OF BIRTH DEFECT CHILDREN

National Birth Defect Registry - Birth Defects per 100 Cases in registry

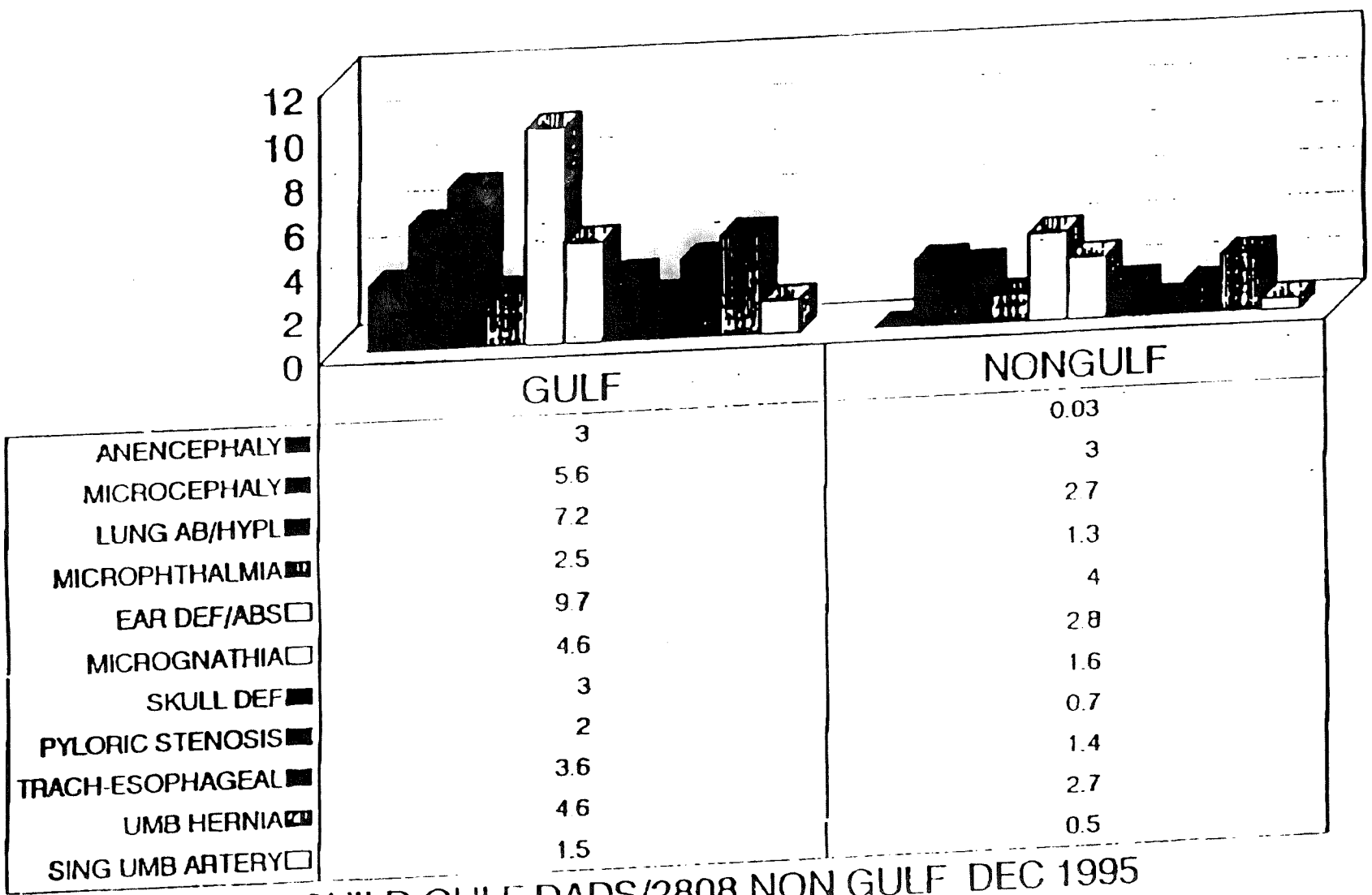


Birth Defects in 194 Child Gulf Dads/2808 Non Gulf Dec 1995

2-2

# ASSOCIATION OF BIRTH DEFECT CHILDREN

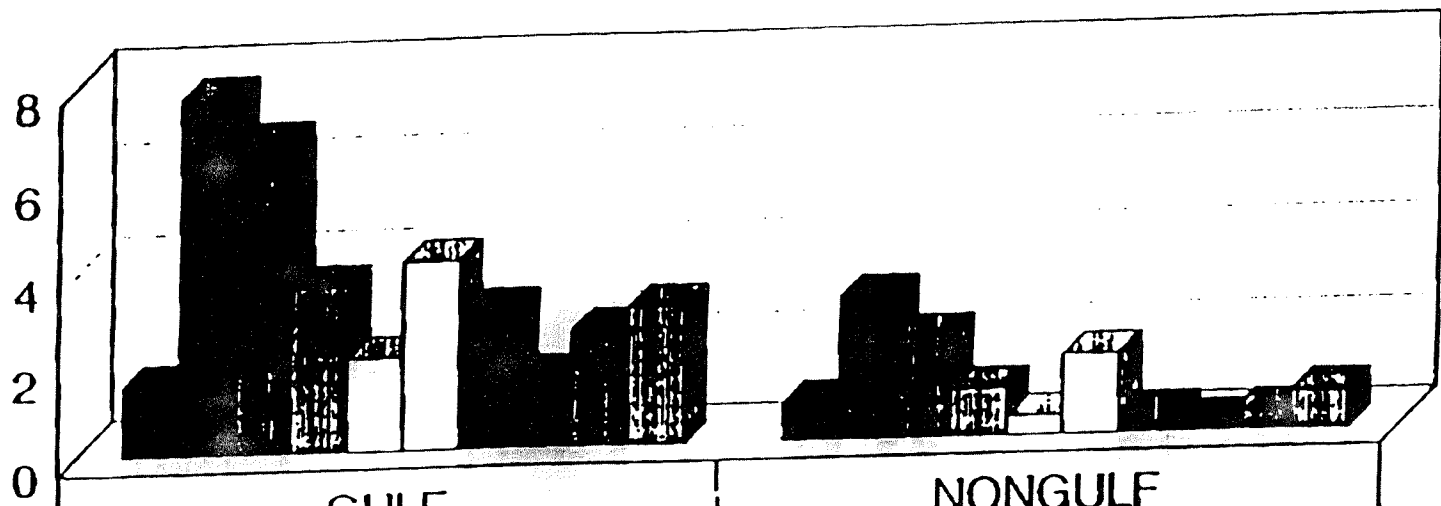
## NATIONAL BIRTH DEFECT REGISTRY - BIRTH DEF PER 100 CASES IN REGISTRY



BIRTH DEF 194 CHILD GULF DADS/2808 NON GULF DEC 1995

# ASSOCIATION OF BIRTH DEFECT CHILDREN

National Birth Defect Registry - Birth Defects per 100 Cases in Registry



	GULF	NONGULF
Tetra fallot	1.5	0.8
VSD	7.7	3.1
ASD	6.7	2.2
Pul Valve Sten	3.6	1
Hypo Left Heart	2	0.4
Patent ductus	4.1	1.7
Coarct aorta	3	0.4
Pulm artery	1.5	0.2
Pulmon atresia	2.5	0.4
Cardiomegaly	3	0.8

Fr-2



729. OCULAR MOTOR APRAXIA, COGAN (MENDELIAN) TYPE

lead toward the object of regard. But, due to initiating the fast phase of the vestibulo-ocular reflex, there is now a contraversive deviation during the pursuit. This is highly characteristic of the clinical picture. The characteristic is the maintained deviation of the eyes which is rotated about a vertical axis.

In contrast to the defect in voluntary eye movements, the patient makes normal random movements of the eyes and makes a voluntary fixation. Also, contrast to the normal horizontal gaze are the normal vertical movements for all parameters of gaze.

The head thrusts are usually noted at 3-4 months of age when the infant begins to hold his head erect. Prior to this, the failure to fixate an object may be misinterpreted as indicating blindness or cerebral palsy. General development is typically normal, but the child tends to be clumsy in sports and to be a poor reader in the first few years of school. The signs and symptoms progressively improve during childhood and are not known to cause any functional deficit in adult life.

Similar head thrusts and defects of the vestibular and optokinetic reflexes are seen with ataxia telangiectasia and possibly with other defects of the saccadic system, but, unlike congenital ocular motor apraxia, these involve the vertical as well as the horizontal eye movements.

**Complications:** Children are reported to be clumsy and are poor readers in the first few years of school.

**Associated Findings:** A similar ocular motor syndrome occurs frequently in Gaucher disease (type III), occasionally in patients with congenital defects of the midbrain, and rarely in infants with tumors of the pontocerebellar region (two cases). Two cases have been reported with brain tumors in the posterior fossa. Several cases have been reported with midline structural defects of the brain or with vermal aplasia of the cerebellum.

**Etiology:** Autosomal recessive inheritance. Several familial cases have been documented, including one family of apparent dominant transmission, and one occurrence in identical twins. Most cases occur sporadically unaccompanied by other abnormalities.

**Pathogenesis:** Unknown

**MIM No.:** \*21650

**Sex Ratio:** M2:F1

**Occurrence:** Some fifty cases documented

**Risk of Recurrence for Patient's Sib:**

See Part 1, Mendelian Inheritance.

**Risk of Recurrence for Patient's Child:**

See Part 1, Mendelian Inheritance.

**Age of Detectability:** In infancy

**Gene Mapping and Linkage:** Unknown

**Prevention:** None known. Genetic counseling indicated

**Treatment:** Unknown.

**Prognosis:** Symptoms progressively improve during the first two decades of life and are not known to cause any functional deficit in the adult

**Detection of Carrier:** Unknown

**References:**

Cogan DG: A type of congenital ocular motor apraxia presenting with head movements. *Trans Am Acad Ophthalmol Otolaryngol* 1952; 56:853-861

Vasella F, et al.: Cogan's congenital ocular motor apraxia in two successive generations. *Dev Med Child Neurol* 1972; 14:788-796

Zee DS, et al.: Congenital ocular motor apraxia. *Brain* 1977; 100:541-559

Cogan DG, et al.: A long term follow up of congenital ocular motor apraxia. *Neuro-ophthalmol* 1980; 1:145-147

Cogan DG, et al.: Notes on congenital ocular motor apraxia: associated anomalies. In: Glaser J, ed: *Neuro-ophthalmology*. St. Louis, C.V. Mosby, 1980:171-179.

Zaret CR, et al.: Congenital ocular motor apraxia and brain stem tumor. *Arch Ophthalmol* 1980; 98:328-330.

Post-It Fax Note	7671	Date	2/15	# of Pages	6
To	Rep. DAN Temish	From	Betty McKee		
Co: Dent		Co	ABDC		
Phone #		Phone	407-245-7035		
Fax	913-296-0251	Fax #			

In the diagnosis of  
11982:93:700-703

David G. Cogan

VAL

See EHLERS-DANLOS SYNDROME  
Oculo-acoustic cerebral degeneration, congenital progressive  
See NORRIS DISEASE

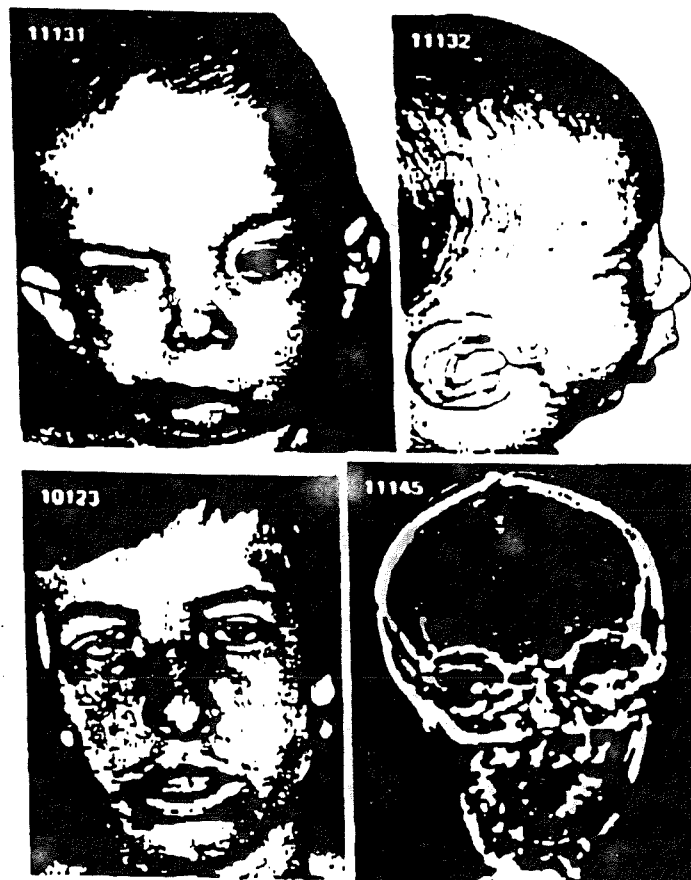
OCULO-AURICULO-VERTEBRAL ANOMALY 0735

**Includes:**

- Facio-auriculo-vertebral spectrum
- First and second branchial arch syndrome
- Goldenhar syndrome
- Goldenhar-Corlin syndrome
- Hemifacial microsomia

**Excludes:**

- Acrofacial dysostosis, Nager type (2167)
- Acrofacial dysostosis, postaxial type (2126)
- Anus-hand-ear syndrome (0072)
- Branchio-oto-renal dysplasia (2224)
- ChARGE association (2124)



0735-11131-32 Facial asymmetry secondary to hemifacial microsomia. 10123: Cribriform of upper eyelid, abnormal auricles and unilateral facial hypoplasia. 11145: X-ray demonstrates right-sided hypoplasia of the face and right mandible.

March 10, 1996  
Room 522-S

A meeting was called to order by Rep. Timesch for the purpose of discussing a federal and a state resolution which will be introduced to the legislature on Wed. March 15, 1996. The state resolution calls upon state agency heads to take action to "create a State register that would include spouses and family members of veterans and anyone else in the State of Kansas that has symptoms of Gulf War illness for the purpose of identifying and compiling a record of those ill."

Present were the following:

- State Representative Dan Timesch, who drafted the resolutions,
- Stan Teasley, Executive Director of the Kansas Commission on Veteran Affairs
- Norma Shull representing V.A. Medical Center
- Jim Bunker, 1st Jr-Vice Commander of Disabled American Veterans
- Lynn Hall, Jr- Vice Commander of Veterans of Foreign Wars Dept. of K.s.
- Joe de la Torre from Governor Graves office
- Lee Stolfus, State Chairman of Veteran Affairs Rehabilitation Commission
- Ralph Snider - Assistant Adjutant for the American Legion
- Dr. Steve Potsic, Director of Health, Kansas Dept. of Health and Environment
- Perry Henault, Gulf War Veteran

Representative Timesch began the meeting at 2:05 p.m. After all present introduced themselves, Rep. Timesch briefly discussed legislation being worked on by six other states to do something to address the issue of Gulf War Syndrome. He stated that Ohio has received \$100,000 to do a comprehensive study to determine the medical effects of Gulf War Syndrome as well as employment, security and emotional and family problems that have occurred. He cited Illinois is working on legislation to set up an assistance program. He then spoke briefly about a Federal and a State Resolution he has drafted and plans to introduce to the legislature this week. The Federal Resolution contains the same language as the other states. The State Resolution is based on Illinois' State Resolution urging the governor, Secretary of Health and Environment and various state department heads in the State of Kansas to set up a commission and

2-6

department head to accept funds to do various things with regard to Gulf War Syndrome. Rep. Timesch stated that the purpose of the state resolution was to call for the design of a Gulf War Registry for spouses, family members or anyone complaining of Gulf War illness and emphasized that the resolution in no way attempted to diagnose a condition. Rather, the intent was to know how many people in Kansas have symptoms or illness and to provide opportunity for an examination. This examination will provide a data base only and it was again emphasized by Rep. Timesch it would not be used to diagnose an illness, that the intent was not to solve a problem but rather to have a registry so "we'll know where these people are and they can have an exam and will know that it could be used somehow." He also emphasized that this was not "his" plan but rather the concerted efforts of those interested in this issue. He called upon representatives of the DAV, Amer. Legion and VFW to get the information out to their members and others on what's available encouraging monetary support for this plan. Dan suggested that any monies coming in from the private sector could be sent to the Dept. of Vet. Affairs where the monies could be put into registry examinations and suggested that Health Dept. might be the data-collecting base. He stated there are 707 Gulf War Veterans in Kansas on a federal registry developed by the federal government.

On inquiry by Rep. Timesch, Norma Shull stated that the Federal Dept. of Veteran Affairs has allocated \$2 million for a limited examination program. This program, which expires on Sept. 30, 1996, will be limited to the first 460-500 people who call in. She stated that to be eligible a spouse or child must be on the Persian Gulf registry and suffering from and illness or disorder and have an interest in participating in the exams. Mr. Teasley asked Ms. Shull what the money will be spent for and she replied it would be used to develop protocol for the examinations. Mr. Bunker gave his personal testimony about his participation in the examination program. After further discussion between Teasley, Bunker and Shull regarding the use of the allocated federal funds, Ms Shull stated she has not seen any protocol for exams as yet. She referenced Public law 103-446 Veterans Benefits Improvements Act-1994, Section 107-Evaluation of Health Status of Spouses and Children of Persian Gulf War Veterans but stated that she is unsure what direction the VA or Federal Government is going on this or is sure the VA will be conducting exams.

Mr. Bunker, returning to the resolutions, informed those present that the

Kansas National Guard has a computer server at Forbes to get people on a registry through internet. He suggested a format as follows: Name, Spouses Name, unit, etc. with basic questions that include symptoms of illness; mailing form to Mr. Teasley; sending out surveys and questionnaire; placing received information into the data base. Rep. Timesch inquired about Mr. Bunker's initial entrance on the Gulf War Veterans Registry. He expressed concern about the length of time between the first registration protocol to now. Mr. Bunker stated that the paperwork concerning protocol has increased from a small single card with questions on it to a 22 page document. Mr. Stolfus and Mr. Bunker discussed who and how many were on the registry. Rep. Timesch emphasized once again that the resolution addresses spouse and child but went on to say that there are 707 Kansan veterans and, according to President Clinton in an address to VFW, 55,000 veterans in the U.S. on the Gulf War Registry.

Mr. de la Torre inquired who "anyone else" referred to in the resolution to which Rep. Timesch replied that it included those who have before possibly "fallen through the cracks", Dept. of Defense workers, personnel and civilian people who went to provide technical support in the Persian Gulf. He explained the emphasis on those not being taken care of with the example of blood transfusions and the ramifications of disease transmittal and cited other states' verbiage in their resolutions that dealt with theories regarding blood transfusions.

Dr. Steve Potsic related his questions to himself regarding a state registry asking himself how to best collect the information and what do you do about what you get. He stated that speaking from a scientific point of view, creating this registry was "flawed". There was no good definition of Gulf War Syndrome and it creates multiple types of symptoms making it difficult to sort out the issues. He stated that Congress asked the Institute of Medicine's National Academy of Sciences which is a non-government agency to review what organizations were doing about this to get an understanding about how to rule on Gulf War Syndrome. The academy reviewed in depth studies that had been done and recommended that one can't take a registry that allows anybody to add their name and try to make any sense about causality. It stated that registries can focus on people with problems and try to help them get solutions or referrals. The downside of a registry according to Dr. Potsic is the cost and the fact that it raises people's expectations. He stated the

following registry implementation problems: protection for those who report, for example, birth defects. Will the veteran report it? Providers (who are reluctant to report unless they have immunity)? Confidentiality-reluctance to be on lists especially with personal data on it. While he praises the groups efforts to try to do something, Dr. Potsic stated he has reservations about what it will accomplish. He stated KDHE is supportive of a resolution that would say the State of Kansas strongly urges Congress, the VA and the DAV in cooperation with solid academic institutions that have solid based scientific studies to prove causality and take 4-5 primary recommendations and say we want you to adopt them and proceed with them. It would give credibility and show people support is moving on this issue. Mr. de la Torre requested Dr. Potsic introduce himself to the group and give the group a list of his credentials and experience. Having done this, Dr. Potsic stated that he wants to find resolution on this issue and wishes to do it in an effective productive way. Rep. Timesch related his frustration and disappointment with the fact that with all the money that has been spent by the Federal Government, there are no documents from the Federal Government on an examination registry. Dr. Potsic spoke to this and reiterated his position on the recommendations from the National Academy of Sciences with hope that now something can be done.

Mr. Bunker related from his experience how, in his estimation, exams are being conducted ineptly, citing examples to support his claim. Dr. Potsic stated he would be willing to offer to help bring recommendations into the resolution

Mr. Hall expressed his concern about the urgency of doing this now and stated that he was speaking on behalf of is VFW group. He questioned what would be achieved for spouses and kids. He and Mr. Bunker discussed the importance of a registry with Mr. Hall still wondering what the purpose is if there is no compensation, e.g., care or treatment.

Mr. de la Torre testified that as a veteran, he was in support of the veterans but that he believed Dr. Potsic made good points especially with regard to the expectations that will be created. He suggested changing the language of the resolution to "give it more meat."

Rep. Timesch reminded those present that it was necessary for this to be done as a group effort and that nothing can be done without private support from organizations.

Gulf War Veteran, Perry Henault was present and gave testimony about his son, Brendon's disease possibly being the result of his exposure in the Gulf War. He explained that Brendon has Golden Har Syndrome detailing the physical deformities indicative of this disease. He related that the incidence of this disease is markedly high among children of Gulf War Veterans. He wants a register to find out how many people are out there who are affected and to put a stop to it. On inquiry by Mr. de la Torre regarding the government claiming responsibility for Brendon's birth defects Mr. Henault stated they denied it.

Rep. Timesch suggested they all go back and discuss what they've learned here and come together again, if possible, in 2 weeks or so when the resolution should be out of the House and into the Senate. Again, he emphasized that the proposal was theirs as well as his.

Mr. Stolfus expressed his appreciation to Rep. Timesch and stated that his group would get information out in the American Legion's Sunflower letter and that he would be going to Washington to meet with VA people and offered to take information with him.

Meeting adjourned at 3:21 p.m.

2-10

Ladies and Gentlemen,

My name is Leslea Mosher Jones. I appreciate being able to present this information to you this morning. I am here in a multifaceted role — as a veteran, a military family member and as a parent. I also have a progressive disability caused by exposure to toxic chemicals.

As a civilian, I can say from personal experience that the ONLY thing more frustrating, exhausting and yes, even humiliating than trying to gain assistance from our state's service agencies, has to be the grinding, "blame the victim" process our veterans have to go through to gain assistance or benefits for service connected disabilities.

Your support of Resolutions 5046 and 5047 can do a great deal to help not only our Desert Storm veterans, but those from all wars and conflicts. It can be a message to those who have risked their lives for our country, that the State of Kansas clearly sees through the sham of the Department of Defense's ineffective investigation of the Gulf war illnesses. It can demonstrate that our state does not ascribe to the "use them and then loose them" mode of thinking that has been demonstrated by those who have directed our Armed Forces.

Your support of these Resolutions can speak to the wife or husband who's partner is caught in the throes of an illness that is not only denied by the Military establishment but by a large segment of the civilian medical community as well. Your support can demonstrate to veterans and their families that, at least in Kansas, they have not been used up, and forgotten after they became too ill to be considered "useful." It could these Kansans that you hear and share their pain, loss and disillusionment, that you are seeking a means of resolving it.

I could spend a great deal of your time describing the gut wrenching, heart breaking experience of watching my husband struggle with an illness caused by toxins which our government assured us were safe. I can portray to you the infuriating frustration of being unable to help as he has struggled with the neurological affects of those toxins as they

*Exhibit 3*  
*Federal and State agencies*  
*3/21/96*  
*Attachment 3*

progressively effect his psychological and emotional functioning. The "support" he has received has primarily been increasing dosages of anti-depressants and similar psychiatric drugs, which only serve to further hamper his ability to function. However, I am sure that Mr. Bunker has been able to provide you with numerous examples of similar situations.

So allow me to give you a brief glance into another aspect of the importance of the Resolutions which you have before you.

Place yourself in the position of having a child with a life threatening illness. Can you imagine how you would feel if you knew that illness was somehow connected to something you had done, that you were somehow responsible....no matter how unintentionally? Thousands of veterans' families are in precisely this position.

The pain, grief and guilt of this experience is compounded by the frustration of trying to procure an accurate diagnosis of your child's health problem. For you see, it has been our experience that it is almost political suicide for a health professional to have the audacity—no matter how truthful or valid—to acknowledge an illness's being caused by toxic exposures. The only individual within the state who we have found to have the fortitude to take this stand is Dr. William Hinshaw of Wichita.

Meanwhile, our most precious resource, our children are bearing the brunt of the Department of Defense's inability or unwillingness to acknowledge both the validity and reality of not only the Desert Storm illnesses, but those of the Vietnam veterans as well. This is mentioned because of the haunting similarity in the illnesses. Your support of these resolution may prevent the Desert Storm veterans having to wait twenty years before the reality of their experiences is confirmed.

My step-daughter, Melissa is a beautiful, highly intelligent young lady with a natural graces and athletic ability. In fact she is reportedly one of the better female



athletes (for her age) in her county. But for the past year she has been increasingly entangled in the web of a worsening, rare disorder known as Goldenhar Syndrome. In the past six months her illness has progressed rapidly and the varied attempts to find an effective treatment, needed support, or even a knowledgeable physician. Our efforts to find help for her have been an escalating round robing of conflicting diagnosis and innumerable medical appointments---ALL civilian, as the military hospitals are of little help. Consider the expense of this process for people who are existing on Social Security Disability and military retirement. Consider how much more difficult it is for those veterans who do not even have these resources.

How would you answer the question Melissa asked me: "Why am I sick, why won't they tell us what's wrong? Am I going to die?"

I know clearly the prognosis of my own chemically induced illness, yet I cannot share this with her and risk hanging a mantle of despair or haplessness on the shoulders of this young girl who is just entering what is termed "the best years of her life." Nor am I comforted by the knowledge that there are thousands of Melissa's across the country. We have already experienced the loss of a child, admittedly from an entirely different reason. But without your support of these Resolutions it will almost assuredly happen again, not only for us, but for many other veteran's families. Could you tell Melissa that she will not die, because you are doing your best to help find a reason for her illness and the illnesses of all the other children and family members?

As a student who has done a great deal of research in these issues, let me share a small amount of what I have discovered about the Gulf War illnesses:

The United States Senate's "Is Military Research Hazardous to Veteran's Health?" report, dated December 1994, delves extensively into the Desert Storm illnesses and demonstrates conclusively that the Department of Defense not only knows the cause of the disorders, but is directly responsible for

them as well (Veterans, 1994).

By federal law, DOD may use an unapproved vaccine or investigational drug *only* under the Investigational New Drug Procedure. This protocol requires that *all* individuals receiving these medications must give informed consent, be told of potential risks both orally and in writing, must be able to choose *freely* whether or not to participate, and distribution of the products must be carried out under carefully controlled conditions where safety and effectiveness can be evaluated. This point is essential since none of the vaccines used on Desert Storm participants, military or civilian, were cleared for such usage by the Food and Drug Administration.

Despite billions of dollars in studies, DOD had no drugs or vaccines to safeguard against chemical nerve agents and biological toxins. Pyridostigmine bromide, which is a carbamate nerve agent itself, was used in hopes it would protect against exposure to the nerve gas Sarin. While it had been cleared by FDA for treatment of myasthenia gravis, Pyridostigmine had *not* been cleared for repeated use in healthy individuals as a nerve agent antidote or for any other purpose. DOD was warned that the compound could cause immune system damage which would be similar to the symptoms of myasthenia gravis and damage from it would be "*extremely difficult, if not impossible to diagnose*". (Veterans, 1994).

The botulinum toxoid used in Desert Storm was an unapproved vaccine used to protect laboratory workers and others who may be exposed to botulism by ingestion. The drug used during Desert Storm was over 20 years old and had elicited concerns about its safety. Further, no testing showed it would be effective in preventing illness when an individual was exposed to airborne botulism toxins.

The anthrax vaccine was FDA approved for individuals whose skin was likely to come in contact with contaminated animal products. No studies had shown it would be effective in protecting individuals from the aerosolized type of anthrax

likely to be used in biological warfare (Veterans, 1994).

In addition, research conducted by Dr. James Moss, a scientist for the U.S. Department of Agriculture, revealed the probability of interactions between the vaccines administered to Desert Storm participants and pesticides they were exposed to during the conflict. His study showed that, when used in conjunction with Pyridostigmine, the common insect repellent DEET became almost seven times as toxic as when it was used alone. Similar results were seen when both DEET and Pyridostigmine were combined with the compound permethrin, used to impregnate the desert sand colored military uniforms of the Gulf war. Although his findings were consistent with concerns voiced by military researchers, Dr. Moss was told to "keep quiet".

Despite intervention by Senator Rockefeller, Dr. Moss's three year contract with USDA was not renewed and the organization has no plans for following up on his research (Veterans, 1994).

The Veteran's Affairs report concluded that the Department of Defense was guilty of numerous violations of the Nuremberg Code. The Code requires (as referenced in the Committee's study) research participants *must*:

1. have the legal capacity to consent, must freely choose to participate— without coercion,
2. know the nature, duration and purpose of the experiment, and
3. be informed of any/all potential hazards and risks to current and future health.

This information must be presented to the participant *both orally and in writing* and the person *must fully understand* the information. "The Nuremberg Code contains no provision which allows any country to waive these requirements during wartime or because of the threat of war" (Veterans, 1994)

On February 23, 1993, page H781 of the Congressional Record, titled "Help for Our Heroes", Senator Gross, is speaking of the veterans who were used as unwitting guinea pigs in the testing of nerve and mustard gas, and lewisite testing and stated:

I do not think it would ever be proper to use human beings as guinea pigs for this type of testing. But in fact that happened. But what really makes it inexcusable and removes all the debate, all the potential debate about whether we should or should not use human guinea pigs for the testing is the fact that these individuals did not know.

The Committee also found the Department of Defense to be guilty of violating the 1975 Helsinki Agreement which allowed for "proxy" consent to be given in certain cases where subjects may be legally incompetent to give consent for participation in experimental situations. *"Proxy consent for legally competent military personnel who participate in military research is not considered appropriate under the Nuremburg Code or the Helsinki Agreement"* (Veterans, 1994).

The report continued, stating that DOD research has been in direct conflict with the regulations known as the "Common Rule" which prohibits the use of federal funds in experiments involving human subjects *unless* the subjects have given specific, informed consent *in advance*.

Finally, the report also challenged the Feres Doctrine, which prevents servicemembers from suing the Department of Defense for damages as a result of negligence on the part of military leaders. They clearly stated, *"Congress should not apply the Feres Doctrine for military personnel who are harmed by inappropriate experimentation when informed consent has not been given"* (Veterans, 1994).

Your support of these Resolutions can do a great deal to restore the shattered trust of these veterans in the government of their state and send a clear message to the Department of Defense that it is time to "cut to the chase" and

get honest with those who have served and risked their lives. It can also clearly tell them that the people of our country are becoming increasingly aware of the web of dectet and betrayal which has clouded their dealings with veterans for far too long.

I thank you for your time.

Leslea Mosher Jones  
1301 SW. 16th Street, Apt 3  
Topeka, Kansas 66606  
233-7109

United States Senate Committee on Veterans Affairs. (1994, Dec.). *Is military research hazardous to veteran's health? ..Lessons spanning half a century.* (Committee Print-S-Prt. 103-97.) Washington, D.C.: U.S. Government Printing Office.