

Approved: February 23, 1999
Date

MINUTES OF THE HOUSE COMMITTEE ON HEALTH AND HUMAN SERVICES.

The meeting was called to order by Chairperson Garry Boston at 1:30 p.m. on February 15, in Room 423-S of the Capitol.

All members were present except: Representative David Haley, Excused
Representative Jim Morrison, Excused

Committee staff present: Emalene Correll, Kansas Legislative Research
Norman Furse, Revisor of Statutes
June Evans, Secretary

Conferees appearing before the committee: Richard E. David, M.D., Comprehensive Epilepsy Center,
KU Medical Center
Susan Arthurs, President/Executive Director, Alliance for
Epilepsy Research
Linda Lubensky, Kansas Home Care Association

Others attending: See Attached Sheet

Staff gave a briefing on **HB 2237, HCR 5013, HCR 5014 and HCR 5015**. **HB 2237** changes 'ombudsman' to 'advocate' and changes 'state long-term care ombudsman' to 'long-term care advocacy' services for the aged Kansas residents. **HCR 5013** urges each member of the Kansas Congressional delegation to support prior rules and regulations regarding organ procurement. Since Kansas is a small state it is better to make organs available on a national basis. **HCR 5014** urges the establishment of an interdisciplinary council on brain seizures. Kansas Medical Center's comprehensive epilepsy center, in conjunction with other institutions, is developing a warning device that would remove the unpredictability of the seizures, thus, improving the afflicted person's quality of life. **HCR 5015** requests Congress to rescind the provisions of the Balanced Budget Act of 1997 related to the interim payment system for medicare home health services.

The Chairperson opened the hearing on **HB 5014 - Establishment of an interdisciplinary council on brain seizures**.

Richard E. Davis, M.D., Interdisciplinary Medical Research Institute, KU Medical Center, testified as a proponent for **HCR 5014**, requesting creation of an institute specifically for interdisciplinary medical research, a formal body of scientists which would encompass specialists from all of the appropriate basic, applied and clinical science.

The purpose is to evaluate, sponsor and fund scientific medical research which of necessity and by the design requires interaction and contributions from ordinarily separate branches of science, disciplines which traditionally tend to operate in non-interactive circles. Each of their skills may be foreign to their cousin sciences, yet together they could accomplish that which singularly they cannot. (See Attachment #1)

Susan Arthurs, President/Executive Director, Alliance for Epilepsy Research, testified as a proponent to **HB 5014**, stating she was an airline pilot and at age 39 had a seizure in her sleep. She lost her airline pilot's license, driver's license and went from being fiercely independent and self sufficient to being totally dependent. Dr. Osorio's research is giving hope to patients with epilepsy. (See Attachment #2)

Dr. Osorio, Director, Comprehensive Epilepsy Center, KU Medical Center, testified as a proponent to **HCR 5014**. Epilepsy is the most prevalent serious neurologic disease across all age groups, it also has the highest potential for full rehabilitation and prevention. Epilepsy defined as 2 or more unprovoked seizures afflicts 1% of the population of industrialized and 5-10% of the population on-industrialized countries. A conservative estimate puts the number of cases at 50 million worldwide. The direct and indirect costs to our nation are estimated at 43 billion/year and to Kansas at nearly half billion/year. Up to 42000 Americans die each year as a direct consequence of seizures. Unpredictability of seizures is the main cause of disability, which in turn is the single largest contributor to cost of care.

CONTINUATION SHEET

MINUTES OF THE HOUSE COMMITTEE ON HEALTH AND HUMAN SERVICES, Room 423-S of the Capitol at 1:30 p.m. on February 15, 1999.

Dr. Osorio is doing research on an automated detection device which predicts the onset of a seizure and showed slides of how this device works. (See Attachment #3)

The Chairperson closed the hearing on **HB 5014 - urging the establishment of an interdisciplinary council on brain seizures.**

Representative Wells moved and Representative Toelkes seconded an amendment on page 2, line 14, inserting "race, origin" between "groups" and "and." The motion carried.

Representative Wells moved and Representative Lightner seconded to move HCR 5014 out as amended. The motion carried.

The Chairperson opened the hearing on **HCR 5013 - urging each member of the Kansas Congressional Delegation to support prior rules and regulation regarding organ procurement.**

Representative Wells moved and Representative Swenson seconded to move HCR 5013 out of committee favorably and place on the Consent Calender. The motion carried.

The Chairperson opened the hearing on: **HCR 5015 - Memorializing the Congress of the Balanced Budget Act of 1997 related to an interim payment system for medicare home health services.**

Representative Long moved and Representative Storm seconded to move HCR 5015 out of committee favorably. The motion carried.

A proponent for the bill stated she would like to deliver her testimony.

Linda Lubensky, Executive Director, Kansas Home Care Association, testified as a proponent to **HCR 5015**. The Balanced Budget Act of 1997 included a number of provisions, which have impacted Medicare home care in Kansas. The most devastating has been the implementation of the Interim Payment System (IPS). The IPS not only included major cuts in reimbursement, but also created a new aggregate per-beneficiary limit. Each agency's limit is based on agency specific utilization data from 1993-94. Consequently, our state's providers, who had a low utilization history, now have some of the lowest per-beneficiary limits in the nation. (See Attachment #4).

The Chairperson opened the hearing on **HB 2237 - Concerning redesignation of the state long-term care ombudsman as the state long-term care advocate.**

Representative Landwehr requested an amendment that would include all ombudsman and all advocates except for Workers Compensation.

Representative Henry stated the amendment would need to be in writing

Representative Gilmore stated this needs fine-tuning.

Representative Bethell asked who is going to watch over these agencies.

Representative Landwehr stated she could come up with final language and would have an amendment in a day or two.

The Chairperson suspended the hearing on **HB 2237** until February 16 or 17.

The meeting adjourned at 3:00 p.m. The next meeting will be February 16.

Written testimony only on **HCR 5014**: Gilbert Strang, Massachusetts Institute of Technology, (See Attachment #5); Alexander Troster, Ph.D., KU Med Center (See Attachment #6); T. E. Duncan, Department of Mathematics, K.U.; (See Attachment #7); Dr. David Morrison, St Luke's Hospital, (See Attachment #8)

CONTINUATION SHEET

MINUTES OF THE HOUSE COMMITTEE ON HEALTH AND HUMAN SERVICES, Room 423-S of the Capitol at 1:30 p.m. on February 15, 1999.

The meeting adjourned at 3:00 p.m. The next meeting will be February 16.

HUMAN AND HEALTH SERVICES

DATE February 15, 1999

| NAME | REPRESENTING |
|--------------------|------------------------------------|
| Rick Davis, M.D. | Epilepsy Research |
| Susan Arthur | Epilepsy Research |
| IVAN OSORIO | KUMC |
| Stacy Soledad | Alein & Weir Chtel. |
| Marlene Reed | KU |
| Matt Hickam | Office of Long-Term Care Ombudsman |
| Michelle Peterson | Peterson Public Affairs Group |
| Debra Zeh | KAT+BA |
| Derek A. Baylock | Intern for Teresa Sittenauer |
| Carmen Dix | KDHE |
| LINDA Lukensky | KS Home Care Assoc |
| Terri Roberts | Kansas State Nurses Assn. |
| Carolyn Muddendorf | Ks St Ns Assn. |
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A PROPOSAL TO CREATE AT
THE UNIVERSITY OF KANSAS MEDICAL CENTER

INTERDISCIPLINARY MEDICAL RESEARCH INSTITUTE (IMRI)

An Institute is defined by Webster as an organization for the promotion of a cause. Indeed, Webster gives a specific example: "a research institute."

Our cause and request today is for the creation of an institute specifically for interdisciplinary medical research, a formal body of scientists which would encompass specialists from all of the appropriate basic, applied and clinical sciences.

Its purpose is to evaluate, sponsor and fund scientific medical research which of necessity and by the design requires interaction and contributions from ordinarily separate branches of science, disciplines which traditionally tend to operate in non-interactive circles. Each of their skills may be foreign to their cousin sciences, yet together they can accomplish that which singularly they cannot.

Such interdisciplinary research bodies exist or are being created in small but growing numbers at major universities. They offer solutions to significant human health problems that no one or two independent scientific disciplines can provide. As the more obvious, singular human illnesses have been discovered (pneumonia caused by a single bacteria or virus), we are left with the more complex diseases (epilepsy, cardiovascular diseases, etc.) which for fullest understanding and eventual cure or prevention, require the knowledge and skill of a wider variety of specialists to interact in the study, research and resolution of such complex medical diseases.

Just such an example of interdisciplinary research is taking place at the KU Medical School today, a research endeavor created by and under the direction of Dr. Ivan Osorio, a professor of neurology and a specialist in the area of epilepsy. The truly remarkable accomplishments to date by Dr. Osorio and his multidisciplinary team of colleagues has only been possible by the diverse interaction of many scientists from the basic fields of mathematics and computer science from the University campus in Lawrence; by the applied sciences of the fields of engineering; and by the medical clinical sciences of neurology, neurosurgery and nursing.

A brief presentation of this unique and exciting interdisciplinary research project will be made by Dr. Iván Osorio. You will see for yourself the scientific breakthrough occurring at Kansas' own Medical Center's Comprehensive Epilepsy Center.

But please note - This remarkable team of diverse specialists in science has not been easily funded. Its current work's financial support is about to cease. Yet this project is of such substance that it has been funded twice by the National Institutes of Health. Yet it has lacked local support because of the unusual non-traditional requirement of diverse specialists on two campuses interacting regularly. Such interdisciplinary endeavors are

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not ordinarily represented in any one department's budget. Yet by allowing it to continue to fullest fruition, Dr. Osorio's research offers the promise of alleviation of one of humanities oldest diseases, one not frequently discussed openly or easily in society – epilepsy. This major deterrent to the recognition, support and financing of research to find the means of prevention and the cure for epilepsy will also be discussed by Ms. Susan Arthurs, both a victim and a crusader to conquer epilepsy. Her singular commitment has created the Alliance for Epilepsy Research, a grass roots beginning to help support and fund multidisciplinary efforts like Dr. Osorio's. But their best potential for fund raising will never reach the dollars necessary to fund fully major interdisciplinary medical research.

In presenting Dr. Osorio to you, I urge you to realize the original research project you are about to see is a rare breakthrough occurring on our mutually beloved turf at the great University of Kansas Medical Center. I urge you also to recognize the major significance in creating a permanent institute to focus on and provide the means for just such interdisciplinary research as Dr. Osorio's. To create such an Interdisciplinary Research Institute would not only guarantee the continuation to success of Dr. Osorio's project, it would assure that the KU Medical Center would be front and center in a new era of complex scientific research which offers solutions to many of humanities serious and complex health problems—possible only by interactive and team effort from many different scientific disciplines. Such an Institute would eventually go far beyond any single project, each project evaluated and approved of by an interdisciplinary team of University of Kansas scientists. As funding was made available by the Kansas Legislature through the University, such badly needed funding, now non-existent, would join with other private, foundation and governmental resources to achieve their noble ends.

It is now my pleasure to introduce to you Dr. Iván Osorio—Associate Professor of Neurology and Director of the Comprehensive Epilepsy Center at the KU Medical Center.

Richard E. Davis, M.D.
Curriculum Vitae attached

Kansas State House of Representatives
Health and Human Services Committee Hearing on HCR 5014
February 15, 1999

Comments by
Susan Arthurs, President/Executive Director
Alliance for Epilepsy Research

I have epilepsy. I have a very different perspective on the importance of epilepsy research, but more on that later. First, I want to briefly tell you about the path my life has taken and how the Alliance for Epilepsy Research began. My story is an example not only of the total upheaval epilepsy can cause in a life, but also of the power one seizure can have. Please keep in mind my story is unique only in its details; the complete disruption is the same for the millions who have epilepsy and for their families.

Twenty years ago, after several other careers, I was hired by United Airlines as a pilot. I was the eighth woman they had hired. (There were over 6000 pilots at that time.) I loved the job. I loved flying airplanes and I knew I would retire at age 60 from United Airlines. I had succeeded. I had found a way to get paid for doing what I loved to do.

Well, I was half right. I retired from United, but at age 39, not 60.

Nine years ago, I had a seizure in my sleep. Literally overnight, I lost my job, my career and my hobby of flying my own small airplane. And I couldn't drive. I lost my wings and my wheels as the result of one seizure. I went from being a fiercely independent and self sufficient woman to being totally dependent.

It is a bit of an understatement to say I was devastated that my flying days were over. I'm embarrassed to admit my identity was so wrapped up in being a pilot that I didn't even consider the possibility of having a life threatening problem. A first seizure at age 39 is often caused by a tumor, aneurysm or a stroke.

It took me five years to admit I had epilepsy. I spent a year feeling sorry for myself, two years running from it by living in a motor home and traveling all over the U. S., one year distracting myself with graduate school and one year trying to get my disorder diagnosed as something more palatable to the FAA.

After taking out my frustrations on my neurologist, Dr. Osorio, for about two years and giving him a hard time because there were so few answers, he told me about his research on predicting seizures. There is one word to describe what settled in as I began to fathom what he was doing and understand where it could lead. That word is HOPE. Hope because someone was doing something and it was something very different.

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Shortly after that, Dr. Osorio suggested I start a grass roots group to advocate for those with epilepsy. I was not really aware of the extent of the problems associated with epilepsy - I knew two people who had it and I was one of them. In my ignorance I shared the general public's perception that everyone with epilepsy had their seizures completely controlled with medication and went on with a normal life.

Dr. Osorio's eighteen years of working in epilepsy health care had resulted in the insight and recognition of the need for and benefits in a patient's organization. I agreed to start this grass roots organization if he would help - I could start just about any airplane in the country but I didn't have a clue how to start an advocacy group.

So the Alliance for Epilepsy Research was started and over the last two and a half years has grown and evolved into a true alliance between patients, their families, the medical community, and the scientific community. The Alliance is unique in that it gives those of us with epilepsy in our lives the opportunity to take some control back from epilepsy. We can help make changes come about rather than just sitting and waiting for something to come down from above.

We now have a core of 25-30 active patients, family members, epilepsy health care workers, and friends in the Kansas City area working on increasing awareness of epilepsy and raising funds for research. Most of us can't do the research to find the solutions to epilepsy's problems but we can raise funds to help. We plan to expand to other cities, states and even countries where similar grass roots groups can also do the same.

The Alliance for Epilepsy Research is a voice for those affected by epilepsy. We see epilepsy research as being not only crucial but as being a tremendous opportunity to be in the lead and do something not being done anywhere else. We know research is the only way to eliminate epilepsy from our lives. We also know the fastest, most creative means to accomplishing that research is to become allied with many diverse individuals and organizations. Our dream is to find better treatments and a cure for epilepsy. I hope you will share our dream.

The University of Kansas Medical Center

Comprehensive Epilepsy Center

Ivan Osorio, M.D., Director

February 15, 1999

To the Honorable Legislators of the State of Kansas

Epilepsy is the most prevalent serious neurologic disease across all age groups; it also has the highest potential for full rehabilitation and prevention. Epilepsy defined as 2 or more unprovoked seizures afflicts 1% of the population of industrialized (Hauser et al, 1996) and 5-10% of the population non-industrialized countries. A conservative estimate puts the number of cases at 50 million worldwide. The cumulative incidence (new cases) is 1.4% by age 32 and 3.3% by age 80 (Hauser and Hersdorffer, 1990). This, combined with the fact that the population over 60 is the fastest growing age group in our country, make epilepsy a public health problem of larger proportions than Alzheimer's Disease, for which there is ample private and government support.

As a chronic illness, epilepsy exacts a heavy toll on those it afflicts and on their loved ones. The emotional, social and economic burden it imposes on the individual, family and society at large is both heavy and cruel. Epilepsy or its treatment greatly limit a person's capacity for enjoyment of life, ability to work, think clearly, drive, attend religious services or public events and maintain or develop fulfilling relationships including marriage. Those directly and indirectly affected by epilepsy live in relative isolation, marginated from society and are without a voice; they have low self-esteem and low expectations (Olsson et al, 1997), which explain in part their being ignored by society. Epilepsy's heavy toll is not merely emotional; **up to 42000 Americans die each year as a direct consequence of seizures** (DeLorenzo et al, 1995). The direct and indirect costs to our nation are estimated at **43 billion/year** and to **Kansas at nearly half billion/year**.

Unpredictability of seizures is the main cause of disability, which in turn is the single largest contributor to cost of care. The inability to work or drive and the serious, frequent injuries among persons with epilepsy, are direct consequences of this apparent unpredictability of seizures. Given that the vast majority of persons with epilepsy are educable, it follows, that accurate prediction of impending seizures, will improve their quality of life and that of their families by freeing them to pursue normal daily life activities and decrease the frequency and severity of injuries, both in a highly cost effective manner. Prediction of seizures, which until very recently was considered unattainable, is now a reality. An interdisciplinary team of scientists at the University of Kansas Medical Center has developed a method (Osorio et al, 1998) which predict the clinical onset seizures by up to three minutes. This algorithm operates out of a personal computer; development of a prototype portable device (See Figure 1) has been successfully completed. Further lengthening the window of prediction and development of automated blockage of seizures are the next logical and necessary steps. These tasks require the participation of an interdisciplinary team of scientists from the fields of epilepsy, engineering, mathematics, physics and computer science and the means to support their efforts. We believe that the most efficient and effective way to accomplish these objectives is through the establishment of an Institute. This Institute would not require a designated building, only support to procure equipment, attract innovative scientists and develop the technical infrastructure necessary to fulfill its important mission. The keys to the unprecedented success in predicting seizures have been the assembly of an interdisciplinary team and the development of a common language and concepts among the different disciplines.

The benefits to our state and nation are substantive and long lasting:

- 1) Improvement in the quality of life of persons with epilepsy and their families.
- 2) Improvement in the quality of medical care in a cost-effective manner. Development of a device for automated blockage of seizures will decrease the cost of epilepsy care in our state by an estimated **\$200 million/year** and in our nation by **20 billion/year**.
- 3) Improvement of the technology base and science in our state and generation of high-tech and manufacturing jobs.
- 4) Increased revenue to the University in the form of royalties and licensing agreements.

We invite you to support this proposal because of its great socio-economic value to humanity and its potential for changing the course of science by breaking down the isolation in which the different disciplines have developed and building a new science for the future.

REFERENCES

- Hauser WA, Annegers JF, Rocca WA. Descriptive epidemiology of epilepsy: contributions of population-based studies from Rochester, Minnesota. *Mayo Clin Proc* 1996; 71:576-586
- Hauser WA, Hersdoffer DC. *Epilepsy: Frequency, Causes and Consequence* Demos NY, 1990
- Olsson I, Chaplin J, Ekstedt J. Extensive rehabilitation needed epilepsy. Different models for varying needs. *Lakartidningen* 1997; 94:2572-2575
- DeLorenzo RJ, Pellock JM, Towne AR, Boggs JG. Epidemiology of Status Epilepticus. *J Clin Neurophysiol* 1995 12:316-325
- Osorio I, Frei MG, Wilkinson SB. Real-Time Automated Detection and Quantitative Analysis of Seizures and Short-Term Prediction of Clinical Onset *Epilepsia* 39; 1998: 615-627



Kansas Home Care Association • 1000 Monterey Way, E2 • Lawrence, Kansas 66049 • (785) 841-8611
Fax (785) 749-5414

To: Health and Human Services Committee for the House
From: Linda Lubensky, Executive Director, Kansas Home Care Association
Date: Monday, February 15, 1999
Re: House Concurrent Resolution No. 5015

On behalf of the Kansas Home Care Association, I appreciate this opportunity to speak in support of House Concurrent Resolution No. 5015, which addresses the impact of the Interim Payment System on Medicare home care providers in Kansas.

The Balanced Budget Act of 1997 included a number of provisions, which have impacted Medicare home care in Kansas. The most devastating has been the implementation of the Interim Payment System (IPS). The IPS not only included major cuts in reimbursement, but also created a new aggregate per-beneficiary limit. Each agency's limit is based on agency specific utilization data from 1993-94. Consequently, our state's providers, who had a low utilization history, now have some of the lowest per-beneficiary limits in the nation.

In the past seventeen months, our Medicare home care providers have made a massive effort to lower their costs while preserving quality of care. We have seen significant lay-offs, elimination of management positions, reduction of services, etc. However, many of our providers have been unable to lower their costs fast enough, or deeply enough, and their expenses remain higher than the reimbursement they receive. Few businesses can continue to operate at a loss, and we have seen the number of closures climb to over 37 Medicare HC providers. Additionally, we estimate that an equal number of "branch offices" have also been closed, a large number of which were located in our rural areas. Daily, I continue to hear from others that are considering giving up their Medicare certifications. Those that continue to operate do so under very difficult situations. The Health Care Finance Administration is already collecting "overpayments" from our agencies and reserves are depleted. Cash flow is a serious and constant problem, as are the heavy care patients agencies continue to see although they know they will not be reimbursed for the care.

In the final days of the last session, Congress did approve a very small increase to provide relief. It equaled about \$1.00 more per nursing visit. Considering that most agencies are seeing losses amounting to 30-50%, this has done little to repair the damage. We continue to see the dismantling of the home care infrastructure in our rural areas that took over twenty years to create. Medicare beneficiaries are losing access to home care services as an alternative to institutional care. Our state administered home care programs (Senior Care Act, Medicaid waiver programs, etc.) are losing providers who no longer can afford to subsidize the rates provided under those programs.

Medicare home care is truly in crisis. We urge you to approve HCR 5015 and join the other states (RI, OK, AL, VT, etc.) that have registered their concerns with Congress. We would be very grateful for your support and assistance.

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Kansas Home Care Association Confirmed Medicare-Certified Agency Closings Since 1/1/98

| Members | Non-Members |
|--|--|
| American Home Health, Wichita | Absolute In Home Care, Wichita |
| Ascend Home Health Services, Lawrence | Access Home Care, Lenexa |
| Bethany Home Care, Kansas City | Alpha Omega Homecare, Wichita |
| Caregivers of Kansas, Topeka | At Your Service, Kansas City |
| Caring Home Health Agency, Newton | B's Home Health Care, Atwood |
| Genesis Home Health, McPherson | Beverly Health & Rehab, Fredonia |
| Heartland Home Health, Halstead | Caring Touch Home Health Services, Wichita |
| Home Health Services, Inc., Garnett | Clinicare Family Health Service HHA, Kansas City |
| House Calls, Inc., Plainville | Columbia Homecare of Overland Park, OP |
| Medbrook Total Home Health, Garden City | Home Health Services of Grand Lake, Yates Ctr. |
| Medbrook Total Home Health, Leoti | HealthCor Inc., Lawrence |
| (and Medbrook branch office in Dodge City) | Hospice Inc., Wichita |
| Medstaff Home Health, Hays | McCurry's Home Health, Kansas City |
| (and seven branch offices in Jetmore, Dodge City, Ness City, Osborne, Phillipsburg, Pratt) | Olsten Health Services, Leavenworth |
| Newton Home Care, Newton | Olsten Health Services, Pratt |
| Olsten Health Services, Wichita | Pleasant Valley Home Health, Sedan |
| Personalized Homecare, ElDorado | Sunflower Home Health, Norton |
| Pirotte Home Health Care, Wichita | Sunflower Homecare, ElDorado |
| St. Elizabeth of Hungary Home Health, Hays | |
| Sunflower Holistic Home Health Care, Lenexa | |
| Sunflower Home Health Care, Winfield | |
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Agencies Medicare Decertified

| Members | Non-Members |
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| | |
| | Ellsworth County HHA, Ellsworth |
| | Professional Home Care, Belleville |
| | South Wind Hospice, Pratt |
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MASSACHUSETTS INSTITUTE OF TECHNOLOGY

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February 8, 1999

The Kansas Legislature
State of Kansas

Dear Legislators:

I am writing as an individual mathematician, who very much wants mathematics to be applied in a way that helps our society and our Nation, and also as President of the Society for Industrial and Applied Mathematics. I am strongly in support of the proposed Institute for Interdisciplinary Research in Epilepsy. The goal of controlling seizures (and anticipating their onset in time for control) absolutely needs the joint efforts of doctors and scientists and engineers. It is a difficult technical problem, because the signals from the brain give only a short and hard-to-recognize advance warning of the seizure. Progress has been made but there is a lot still to do.

Most of us are not touched by epilepsy, but the daughter of my next door neighbors had a fatal seizure and I became very conscious of the danger and the difficulty presented by epilepsy. I have had contact for several years with Dr. Iosorio and I am very favorably impressed by his leadership. He recognizes the scale of the problem and he knows the details — medical and scientific. It will take hard work on these details, by people with different skills, to move forward. I am convinced that progress is possible.

I believe that this Institute is an investment in our future that will bring credit to the state and intense appreciation by those whose lives are directly affected. Thank you for the chance to express what I feel. It will be a pleasure to see the successful outcome of this joint work on a hard problem.

Very best regards,

Gilbert Strang.

Gilbert Strang
Professor of Mathematics, M.I.T.
President, Society for Industrial
and Applied Mathematics

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The University of Kansas Medical Center

University of Kansas Hospital
Center for Neuropsychology and Cognitive Neuroscience
Director: Alexander I. Tröster, Ph.D.

February 11, 1999

To the Honorable Members of the Kansas State Legislature:

I am indeed grateful to learn that Professor Ivàn Osorio has been given the opportunity to address you and to share with you not only some of the issues facing Kansans with epilepsy, but also some of the cutting edge, interdisciplinary research that he directs at The University of Kansas Medical Center's Comprehensive Epilepsy Center. As will become evident from his presentation, Dr. Osorio's research is at the forefront of science and technology. His early success in preclinical seizure detection by applying complex mathematical algorithms to electroencephalographic (EEG) data has already been featured in media across the nation. My purpose in writing this letter is not simply to congratulate Dr. Osorio and his colleagues. Rather, it is with a sense of great excitement that I would like to convey, from the perspective of a neuropsychologist and cognitive neuroscientist, some of the implications of Dr. Osorio's current and planned research for persons with epilepsy.

Neuropsychologists are concerned with brain-behavior relationships. From a clinical standpoint, it is their goal to identify and quantify changes in mental functions (e.g., memory and attention) that occur as a consequence of central nervous system disease, and what impact such changes have on an individual's day-to-day functioning and quality of life. Neuropsychologists also seek to identify potential adverse and beneficial effects that medical and surgical treatments of central nervous system conditions have on mental functions, behavior, and quality of life, and to identify those factors associated with favorable and unfavorable treatment outcomes. Experimental research, in contrast, seeks to elucidate component cognitive functions and how neural systems mediate these functions.

Because a full discussion of the neuropsychological and quality of life aspects of epilepsy necessitates a multi-volume work, I highlight here, for illustrative purposes, only some of the important questions that research at the Comprehensive Epilepsy Center seeks to address. It is well known that chronic treatment with antiepileptic drugs can be accompanied by adverse effects on cognition and behavior. Such effects include a dramatic slowing of thought, diminished attention and memory, and fatigue. The staggering economic costs of drug treatment (although more than adequately justified by beneficial effects of seizure control) are compounded by the impact that side effects can have on some person's of quality of life. Side effects can impact employment, education, and the ability to drive and carry out efficiently routine activities of daily living. Comprehensive Epilepsy Center research aimed at the possibility of developing medication regimens which involve taking medications only when needed, rather than on a chronic basis, would reduce economic costs and enhance the quality of life of persons with epilepsy.

The preclinical seizure detection research already mentioned has as one of its goals the elucidation of cognitive changes associated with pre-seizure alterations in brain electrophysiology. The objective of this research is to identify the amount of time an individual has to purposefully act after detection of pre-seizure activity so as to allow a person to respond to an alarm of impending seizure or cognitive alterations precluding the safe execution of current activity (e.g., driving, tool use). Obviously if such an alarm can be developed, persons with epilepsy could engage in many activities currently avoided due to safety concerns. Indirectly, such research would also allow a better understanding of physiologic, rather than only anatomic, brain system processes underlying higher cortical functions.

The hallmark of the Comprehensive Epilepsy Center's research success has been the bringing together of scientists from multiple disciplines, for instance, medicine, physics, mathematics, neuroscience, sociology, and economics, while seeking input from community members. While researchers within each discipline contribute to understanding a specific aspect of epilepsy and its impact on individuals and society, the Comprehensive Epilepsy Center, under Dr. Osorio's direction, has been a home to collaboration that bridges and integrates the separate disciplines' efforts. I am convinced that after hearing Dr. Osorio's presentation you will share my enthusiasm and hopes for the Center's continued success, and my optimism that the Center's success will have an unparalleled impact not only on the lives of persons with epilepsy, but also your constituents. I have no doubt that the Comprehensive Epilepsy Center will be an asset and resource for *all* Kansans.

Respectfully,



Alexander I. Tröster, Ph.D.
Clinical Associate Professor of Neurology
Director, Center for Neuropsychology and Cognitive Neuroscience

The University of Kansas

28 July 1998

Department of Mathematics
College of Liberal Arts and Sciences

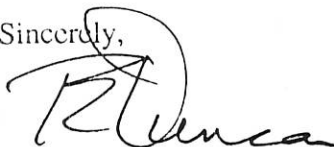
Dr. Ivan Osorio
Department of Neurology
KU Medical Center
3901 Rainbow Blvd.
Kansas City, KS 66160

Dear Dr. Osorio:

This letter is in response to our conversation about the possibility of organizing an institute containing a multidisciplinary group that would include doctors, mathematicians, scientists and engineers who face common problems in different fields. Since your colleague, Dr. Mark Frei, in Flint Hills Scientific was my doctoral student, I have seen your collaborative efforts on the detection of the onset of epileptic seizures develop. This work involves detection, modeling and control. These same problems occur in many other disciplines, e.g. traffic management of telecommunication systems, analysis of economic time series and fault detection. The mathematical techniques are similar, so it would be advantageous to have a multidisciplinary approach. Our group, Stochastic Theory and Adaptive Control, at the KU Mathematics Department would be enthusiastic about participation in such an activity.

In summary I fully support your activities for the development of a multidisciplinary institute to investigate these common problems and I look forward to receiving further information about the development of this proposal.

Sincerely,



T. E. Duncan
Professor of Mathematics

 Saint Luke's Hospital
of Kansas City

SAINT LUKE'S-SHAWNEE MISSION HEALTH SYSTEM

Office of Research Administration
Tel: 816 932 9844
Fax: 816 932 5179
Email: dmorrison@saint-lukes.org

January 12, 1999

Ms. Susan Arthurs, President
Alliance for Epilepsy Research
PO Box 10351
Kansas City, MO 64171-0351

Dear Susan,

Thank you very much for your telephone call of last week and your follow-up fax memorandum summarizing the concepts for the development of an Epilepsy Institute that would be based here in Kansas City. This is indeed an exciting concept and, in many respects, would fulfill a very real need in this country, as well as be a substantial boon to the Kansas City area. I recognize that this will be a daunting task but one that would be very worth pursuing. I would, therefore, be delighted to discuss with you and your colleagues how I might contribute to these efforts. If you wish, please telephone my Administrative Assistant, Kathy Rode, to determine a mutually agreeable time for us to get together.

With very best personal regards.

Sincerely,



David C. Morrison, Ph.D.
Director of Medical Research
Westport Anesthesia Services/
Missouri Endowed Chair in Research

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