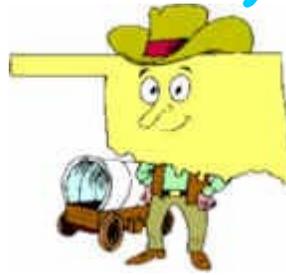


OFFICE OF HANDICAPPED CONCERNS

WILL'S CORNER, OKLAHOMA



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(Serving the Disability Community of Oklahoma)

Betsy Replogle, an Oklahoma Advocate

Betsy Replogle on illness

My long relationship with chronic illness began twenty years ago on December 21, 1984. It wasn't that I had no idea what Dr. Reichlin was going to say. I had read a lot about it, and I knew it was a killer. I knew what the books said. My skin would be stretched tight like a wrapping of cellophane around my body. Inside I felt I had been physically beaten, rolled in broken glass, and set on fire. Renal failure was always a threat. My body was in civil war. But when he told me, it was still a shock. It was like I really wasn't there and this wasn't happening to me. But it was, and I wasn't going to wake up to another reality. I had a crippling disease which was almost always fatal in 1984. I really thought I was going to die but not before a long period of agony. If it were only dying, I think I could have stood it, but the pain in every nerve of my body was a torment that never left. Scleroderma is a rare, crippling

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HAPPY HOLIDAYS, GORE OKLAHOMA

On Saturday, December 11 Steve Stokes and I drove over to eastern Oklahoma to the proud municipality of Gore. Gore, Oklahoma is in an enviable area of the recreational, eastern part of the state near lakes and forests popular with hunters, fishermen, and camping enthusiasts. Lake Tenkiller's southern reaches are a bare six miles to the north surrounded with no less than three state parks: Tenkiller, Cherokee Landing, and Greenleaf State Park which we mentioned in *Will's Corner* summer edition as having handicapped-accessible cabins. To the southeast of Gore lies the impressive Robert S. Kerr Lake which was created by damming a portion of the Arkansas River near the Arkansas line.

Gore boasts a population of 850 people swelled by tourists in season and permanent retirees who have left the razzle dazzle of the cities to embrace the idyllic lifestyle of a by-gone age. Small-town Oklahoma is one, big family built on solid American values where everybody knows you and probably knows your children and grandchildren as well. And lots of those children and grandchildren were out on this beautiful early Saturday afternoon to celebrate Gore's annual Christmas Parade right down Main Street U.S.A.

Steve and I were right in the middle of that parade nestled among several cars of state dignitaries such as State Senator Richard Lerblance of Senate District 7 and Representative Ray Miller of House District 15 whose districts include Gore. The State Department of Commerce was rep-

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OHC web site:

www.ohc.state.ok.us

HAPPY HOLIDAYS, GORE OKLAHOMA (continued)

resented by a smiling Corey Herndon who threw wrapped candy to eager children scurrying on the sidelines to get all the goodies. And then there were real clowns on stilts with funny faces laughing with the excited children and proud parents lining the streets. What would a parade be without a marching band, and music there was provided courtesy of local schools. And don't forget the football queen on that nicely decorated float over there. City officials said that this was the biggest Christmas Parade Gore had ever hosted.

But as much fun as the parade turned out to be, the best was yet to come. Gore had a little town hall meeting right after the parade was over. Mayor Larry Pack was there as well as Vickie Tinscher who is the Deputy City Clerk and Keats Tyler who is the City Administrator. Vickie tells Office of Handicapped Concerns Director Steve Stokes that Gore wants to serve all its citizens regardless of ability. Let's look into that town hall meeting a little closer to find out what they're planning to make this particular small Oklahoma town more accessible.

Vickie Tinscher

"Steve, we're so happy you could come to Gore to join in our celebration. Our community wants to be more accessible to people with disabilities, and we want to know how."

Steve Stokes

"The parade was great. Thank you for inviting me, and thank you for being interested in making your city a friendlier place to people with disabilities. I am sure Gore, Oklahoma is no different from any other Oklahoma town with fully one in five citizens having some type of disability. But I know you

also serve a lot of tourists and retirees in the area who may have disabilities. If your town is accessible, these people with disabilities will want to come here and spend their money. Accessibility is good for business."

Vickie

"Steve, we're just looking at things we can do now with not much of a budget set aside. We want to take things one step at a time."

Steve

"You might start out looking right around this room. This is a public building and as such under Title II of the Americans with Disabilities Act (ADA), it should be accessible to the citizenry. Lever door handles are easier to grasp for me because I do not have full use of my hands. Since I'm in a chair, it is easier for me to use the paper towel dispenser in your public bathrooms if that towel dispenser is at a little lower level. These are things that don't cost much money, but they can make things so much easier."

Keats Tyler, City Administrator

"We want to lay some sidewalks with curb cuts to help people get around town. I think the Department of Commerce may have some grants to do something like that."

Corey Herndon of the Department of Commerce

"We have grants which are not specifically for the purpose of making something ADA accessible although a city could use the money for that purpose if they chose to."

Vickie Tinscher

The City of Gore currently has a 1 cent sales tax which is due to end. We are having an election later this month to allow voters to decide whether to extend this sales tax another year. If the measure passes, we hope to build a new senior citizens center from the ground up which would be totally accessible to people with disabilities."

State of Oklahoma
www.youroklahoma.com

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DEEP BRAIN STIMULATION

**(A Treatment for Essential Tremors,
Parkinson's, Dystonia,
and to be approved for Epilepsy)**

Dr. Paul Francel:

Most of my patients choose to be awake. It is the patient's choice. We always anesthetize the skull, but the brain is actually an amazing thing. You feel nothing during surgery. We put five small screws the size of the screws in your eye glasses into the skull a couple days before the actual surgery. During the surgery, we make a hole the size of a nickel and insert small wires with electrodes on the end into the Anterior Nuclear Group of the thalamus. These electrodes are targeted through computer imaging with 3D high resolution which permits hair-splitting accuracy and is a minimally-invasive procedure which takes only about two hours. The electrodes are then activated a couple months later and the results compared against subjects who are not activated to determine if this procedure will actually reduce or eliminate seizures.

Some patients have uncontrolled seizures which are not controlled with medications. We are involved in a national study here at the O.U. Medical Center to determine if this surgery and the stimulation of the brain through the electrodes can actually prevent seizures from occurring. We are one of the twelve centers in the United States selected to do trials of this procedure. The F.D.A. (Federal Drug Agency) and Medtronic which developed the technology which we insert into the brain are paying for these trials. Candidates for the trial go through our neurologist, Dr. Oomen, who then refers patients to me. For the patients who are selected, all costs are waived. The patient must agree to the procedure and continue with all follow ups for a couple years afterwards.

I think Deep Brain Stimulation has a good chance to be approved as a viable treatment for uncontrolled seizures in the United States. We are half way through the trial now and it will take some time to analyze the data when the trial is over, but the results are encouraging. Deep Brain Stimula-

tion is already an approved procedure for Essential Tremors, Parkinson's disease, and Dystonia. The procedure is very similar in these conditions except that we treat a different part of the brain. The idea is to stimulate an area of the brain to prevent negative symptoms of the disease, and this has actually been quite successful.

In 1997, Channel 4 News of Oklahoma City did a piece on a 63 year old man whose hands shook uncontrollably making it impossible for him to even hold a coffee cup. During filming of the actual surgery, when we inserted the electrodes into the right part of his brain, the tremors stopped immediately. He tells the amazing story that he feels he got his life back, and at the end of the story he is teeing off on the golf course. It was quite dramatic.

I think this procedure has the potential to affect people suffering from uncontrolled seizures as well. Keep in mind, however, that we are only involved in trials now. The procedure is not yet FDA approved for the treatment of epilepsy. We have been chosen as one of the twelve centers in the United States to test Deep Brain Stimulation on subjects suffering from uncontrolled seizures. This is quite an honor.

Research on the brain is escalating. I can foresee a time when we may treat clinical depression, obesity, and even schizophrenia. In obesity we know that something is wrong in the metabolic regulators of the hypothalamus. We are seeing that all these

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More than 10 percent of Oklahomans have a serious mental illness, the highest rate in the nation, according to a survey released today.
The Daily Oklahoman
April 13, 2004

Emergency Preparedness

Are you or a member of your family a person with disabilities? Do you or this other member of your family attend public meetings in your town? How would you evacuate that public meeting hall if there was an emergency? Lots of us have not really thought about that, but some people in Oklahoma City have been thinking about just this subject and have been thinking about it in reference to the new Ford Center in the downtown area which can accommodate up to 20,000 people at one time.

At full capacity of 20,000 people, how many people with disabilities might be in the audience? Oklahoma has about one in five citizens with some form of mental or physical disability which would equate to 4000 people in that arena having some form of disability. We all know that many of those 4000 people have only a mild disability, but what if there were as many as 100 people in the audience who had a severe disability. Some of those people might use a wheelchair to get around. Some of them might be blind or deaf or have any number of other disabling conditions. In the event of a fire, what would happen to these people in the potential chaos which could occur?

It's better to think about this now than to wait until the emergency occurs. Planning is exactly what the City of Oklahoma City and the management of the Ford Center did on the evening of November 15, 2004. They assembled 300 plus civic-minded volunteers including local boy scouts into the Ford Center to discuss their evacuation plan and to do a trial run on how people with disabilities could evacuate the Ford Center in the event of an emergency. All the volunteers were assembled into one section of the Ford Center and were given tags identifying them as having one type of disability. Some people actually got into wheelchairs to simulate evacuation of a person with mobility impairments.

Fire Chief Long of Oklahoma City addressed the volunteers together with paid staff of the Ford Center on what to do in the event of an emergency. He hit the highlights of a 26-page evacuation plan pre-

pared to instruct Ford Center employees, emergency city employees and the general public on what to do in case of an emergency during a major public event. The evacuation plan included various kinds of emergencies as well as details on working with people with various kinds of disabilities. What should a fireman or Ford Center employee do in case of a fire in the building? What should a security guard do in case of a bomb threat which was deemed likely? How should staff escort an individual who is blind in the proper way? How does an employee safely escort an individual in a wheelchair down a flight of stairs? These are things that are worthy of being addressed before an emergency to avoid unnecessary human suffering.

A short film was shown the audience which followed very closely the text of the evacuation plan before initiating a real fire drill using emergency equipment within the center. Staff escorted individuals in wheelchairs to the nearest outer stairwell. Emergency alarms rang across the building and were accompanied by flashing lights to alert individuals who were deaf. People exited the building via the nearest outer stairwell which was reportedly built to withstand four hours of fire before becoming unsafe. Exiting public and staff were encouraged that in the event of a real fire, some smoke could escape into the stairwell exits and people should keep as low as possible below the level of the smoke. The group of volunteers, staff, and city emergency employees safely filed out of the building at street level within a few minutes.

Fire Chief Long talked about a shelter-in-place type of emergency. He stated that in the event of a large, hazardous chemical spill near the Ford Center that citizens should remain in the building until the danger outside was resolved rather than exit into a dangerous situation. In the event of a tornado in the vicinity, people would be led to safe rooms off the lower level of the center until the threat was over passed.

People with different types of disability require dif-

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Emergency Preparedness (continued)

ferent assistance. A person who is in a wheelchair could use two assistants in going down stairs safely and quickly. A person with a guide dog may prefer to have the dog follow the assistant rather than directly lead the individual. People who have a cognitive impairment need simple, direct instructions on what is happening and the best way to remain safe. Safety depends on people with disabilities making known their presence and needs and staff being properly instructed on the needs of people with disabilities.

The Ford Center in Oklahoma City is a prime example where large numbers of the public, many with disabilities, may be assembled at one time. You may or may not have a Ford Center in your community, but I'll bet you have a basketball or football game. Large numbers of people are gathered in local churches and hospitals and schools. Do emergency personnel know how to evacuate people with disabilities under various kinds of emergency? Are people with disabilities aware of emergency exits? Is your community prepared for

all possibilities? Preparation can make the difference between life and death. Our Director at the Office of Handicapped Concerns says, "Safety codes are literally written in blood." Emergency preparedness saves lives.

We want to thank Police Captain Pat Byrne of the Oklahoma City Police Department for his help in arranging this emergency fire drill at the Ford Center in Oklahoma City. Thanks to Fire Chief Long and Tom Anderson also representing the City of Oklahoma City. Thanks to all the SMG staff at the Ford Center including Gary Desjardins, the General Manager and Robin Miller who is the Guest Relations Manager as well as Gloria Pollard who is the Human Resources Manager. Thanks also to the SMG general staff at the Ford Center and civic-minded public in Oklahoma City who played a vital part in preparing for an emergency. And thanks to you in small towns and large cities across Oklahoma who will help prepare your community to safely respond to an emergency in a public assembly of people.

HAPPY HOLIDAYS, GORE OKLAHOMA (continued)

Mayor Larry Pack

"We are also building a sports complex here in Gore which we hope to make accessible to people with disabilities."

Jeff Andrews, architect with ADA expertise

"I have recommended we survey all city buildings to see what we will need to do to get public buildings up to code. Get a committee of citizens to prioritize these things so we can have a place to begin. This needs to be a community effort with everyone pulling together."

Steve Stokes

"It sounds to me like Gore is taking control of their community. Community leadership and community commitment will make a difference for people with disabilities. I can see that you are really serious about doing something. Remember that what you do today to make your city more accessible to

people with disabilities may help you or a member of your family tomorrow. All of us are only temporarily able bodied."

If you have a question about the accessibility guidelines of the Americans with Disabilities Act of 1990, call the Office of Handicapped Concerns' toll free number at 1-800-522-8224. We'll be glad to offer you technical assistance with specific information. If you are a person with disabilities anywhere in Oklahoma, you may advocate for more accessibility in your community. Contact your city council representative with your concerns. Explore ways your community may finance projects which will help its citizens. In the summer edition of this newsletter, we discussed what was happening in Stillwater. Now we feature the community of Gore. We want to visit your town as well to tell the good news of a barrier-free Oklahoma which welcomes all its citizens to participate fully in this dream we call America.

Betsy Replogle, an Oklahoma Advocate (continued)

disease in which the human body turns on itself in savage attack.

It is in a family of autoimmune diseases which you are much more familiar with like rheumatoid arthritis and lupus. My body produces too much collagen which causes my skin to stretch tight and harden. That's what scleroderma literally means—hard skin. If that were all that it affected, I think I could live with it, but it also affects internal organs like the kidneys, heart, and lungs. Connective tissue like ligaments and tendons tighten to freeze the body in grotesque images like a polar blizzard captures falling waters in motion. This hardening of my body inflamed every nerve in screaming revolt, and I was quickly reduced to a deathbed of horror.

Dr. Reichlin is the Vice President for Research at the Oklahoma Medical Research Foundation. He told me about scleroderma, but he also told me not to let the terrible things I had been reading about this thing frighten me. The current literature is already outdated. We are learning new things every day and just because the news was not good today did not mean that it would always be that way. I grasped at this small hope and nurtured it even as I watched this thing progress more rapidly than even the books described. I really thought I was going to die even as I concentrated my energy on that small hope that Dr. Reichlin offered. Maybe I could live long enough until medical research could discover some way to control this horrible disease.

I remember having a dream, and this dream is still real to me today. I was on a mountain in a freezing rain at night. Dr. Reichlin was driving the bus down those dark, twisting roads covered with ice. I was in the back of the bus in my hospital bed, and I knew the danger of the bus sliding off into the void. I knew the danger but somehow I accepted my own helplessness. I trusted Dr. Reichlin to use all his driving skills to bring me safely down that mountainside. Whatever would happen would happen, and it was then that I relaxed for the first time in weeks. I didn't have to control anymore. I accepted what was happening to me however it

Read All About It!

The Office of Handicapped Concerns has published its new book on housing for people with disabilities. Download it from the website www.ohc.state.ok.us or call 800-522-8224 to reserve your copy.

turned out. I rested.

I survived the renal failure on a new drug which helped to break down the extra collagen my body was producing. Trust is a beautiful thing that I don't think I would have ever known if I hadn't faced this crisis. People feel they have to be in control because they don't know how to trust. I trusted Dr. Reichlin to do his best and however the outcome, it would be for my best. The world was okay. My mind was at rest even as the disease raged on.

Scleroderma produced astonishing symptoms which my twelve plus medications only superficially treated. My small blood vessels constricted to cut off the blood to my hands first causing them to turn white, then dark blue, then red again. Contractures appeared on my fingers like cat claws, and I developed ulcers in my mouth which was always dry. My esophagus was scarred with reflux which had the potency of battery acid. My teeth began to decay from the reflux, but I knew I was going to live again. I had a mission from God.

Betsy Replogle on Advocacy

In 1995 I started going to Washington, D.C. to ask Congress for more funding on rheumatology. My family said no, but I went on anyway. I went to

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Betsy Replogle, an Oklahoma Advocate (continued)

Ernest Istook and other members of the Oklahoma delegation asking for money for research. Sometimes I went to key congressional leaders. I told them what I wanted and why. I had no money to offer. I only had my experience and a passion to make a difference. I wanted to be a patient advocate—not a paid lobbyist. Patient advocates have gotten federal funding for medical research doubled in five years. The national arthritis action plan has been funded to the tune of \$10 million. People working together can make a difference. Then something happened to me which turned everything upside down.

Health and Human Services Secretary Tommy Thompson appointed me in 2001 to serve on the Advisory Council of the National Institute of Arthritis, Musculoskeletal and Skin Diseases (NIAMS). I found myself meeting three times annually with a group of doctors and medical researchers of world renown who have final approval on a half billion dollars worth of federal medical research monies. I am humbled by this appointment, and I still ask why me. The only answer I come up with is that I know from a personal level what disease can do. I think that is the part I can add to the equation. I am not a doctor even though I am on a first name basis with people who are

highly respected in their fields. I accept my appointment even like I accepted the devastation that scleroderma waged on my body. I accept the good and the bad.

Some day we may be able to cure scleroderma and other autoimmune diseases. We continue to learn more about this devastating condition. Oklahoma Choctaw Indians have the highest incidence of scleroderma in the world with a rate forty times the average. We don't know why, but we may learn as developments in genetics and new techniques for research and biotechnology appear. Our knowledge is exploding. It is exciting to see it all first hand, and I have a part to play in all of this. Being named on the Advisory Committee is as much a mystery to me as those early days in 1984 as I was hurled into a dance of death with disease and the disability it spawns. I accept today. I accept whatever it brings. Tomorrow is another day, and I have no assurance what it may bring. I have learned to trust that good will triumph in the end.

Betsy Replogle is a patient advocate, and she was born and raised in Oklahoma. In addition to her efforts in Washington, D.C., she serves on the Oklahoma Arthritis Network organized through the State Department of Health.

DEEP BRAIN STIMULATION (continued)

conditions have a biological basis. Just like the man whose tremors stopped, we will be able to treat conditions we have never dreamed before as a result of our research into the mysteries of the human brain.

Dr. Paul Franzel is a Harvard University undergraduate. From there he went on to the University of Chicago where he received his MD and PhD. He did his residency at the University of Virginia which is a premier center for the training of neurosurgeons. Dr. Franzel resides with his wife and four children in the Oklahoma City area.

Working Smart

Being successful is not about how hard you work—it is about how smart you work. Michael LeBoef said, “Devoting a little of yourself to everything means committing a great deal of yourself to nothing.” There is a big difference between activity and accomplishment. Activity is being busy. However, as Henry David Thoreau once said, “It’s not enough to be busy; so are the ants. The question is : What are you busy about?”

CALENDAR OF EVENTS

March 8, 2005

Oasis one-day conference on social services in Vinita, Oklahoma. This is part of a series of grassroots one day conferences on the availability of social services in our state. Contact Sally Selvedge at 800-426-2747 for more information.

March 9-10, 2005

Oklahoma Association of Supported Employment Conference in Tulsa at the Southern Hills Marriott Hotel. For more information, call 405-325-0448.

April 4-5, 2005

Governor's Conference on Developmental Disabilities in Tulsa's Southern Hills Marriott Hotel. For more information, contact Sheree Powell at 405-521-6267.

If you have an event coming up relating to disability, let us know at 800-522-8224 and we'll help you publicize.

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