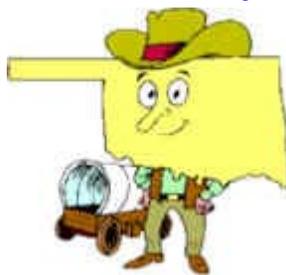


WILL'S CORNER, OKLAHOMA



Volume 10, Issue 1
January, 2009

(Serving the Disability Community of Oklahoma)

Miracle On Hammack Street

Warning:

If you are a person with a weak stomach, you may not want to continue reading this. It contains some graphic details which may detract from the story of one person's suffering and eventual healing from a rare disease.

They called it calciphylaxis, and I can't even pronounce it, but I lived it and I think that is more important than pronouncing it. At first nobody knew what was going on.

In 2002 knots began to appear on my stomach, maybe the size of half a dollar. I showed them to my doctor in the spring of that year, and he took a wait-and-see attitude.

(Continued on page 2)

Advocating in Ada, Oklahoma

Main Street Renovation was a project started by city leaders way back in 1996. Ada wanted to correct a persistent flooding problem on the west end of their downtown area in addition to putting a new face on an area long neglected.

Charlie Jones saw this as an opportunity to improve the accessibility of downtown streets and sidewalks so that people with disabilities could spend their money too.

He wrote a letter to the City Council requesting to get on the agenda for their next meeting. The City Council referred him to talk with the City Manager and the City Attorney.

Charlie pointed out that downtown corners had curb cuts going one direction but often lacked the second curb cut. If an individual in a wheelchair was crossing the street in one direction, they would have to wheel out in the street if they also wished to go the other direction.

He pointed out that the City of Ada did not have an Americans with Disabilities Act coordinator nor did they have a transition plan on how to bring city services into compliance with the law.

Between 1996 and 1998 Charlie talked regularly with city officials as projects came up. The City made curb cuts by the library which did not previously have them. Some of these curb cuts were re-done later because the slopes were too steep and did not comply with the Americans with Disabilities Act Accessibility Guidelines (ADAAG).

Parking lots near Main Street and other downtown streets had

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ODC web site:

www.odc.ok.gov

Miracle On Hammack Street (continued)

But in that hotel room at the family reunion in August, I knew I couldn't wait anymore. The knots on my stomach deepened and widened and burst open in blood, oozing water and pus. It smelled so bad, and I was so ashamed I didn't know what to do.

I saw another local doctor, and he said I had gangrene. I needed to go to the emergency room in Oklahoma City. They said it was not gangrene, but cleaned it out and put a patch on it and sent me back home.

I didn't know what to think. Even the doctors didn't seem to know what to do with me. I felt so alone, and I felt so sorry for my husband who was trying so hard to get to the bottom of all this.

My kidneys began to fail, and I saw a specialist who put me on dialysis. I complained about the boils and knots on my stomach, and they probed in the open sores to find out what it was.

By this time they were so big you could put your hand in up to your wrist. Something was actually eating away my flesh. Puddles of blood collected wherever I was. It was awful.

Bob (my husband) couldn't stand it anymore, and he got on the computer to try to find some answers. He found a specialist in St. Louis, Missouri who knew a lot about this disease.

My body was making tons of calcium, and this was floating to the surface and rotting my flesh. The doctor in St. Louis told me about Dr. Lucas Haragim who was an O.U. Physician in Oklahoma City.

Lucas drove from Oklahoma City to meet us at the Pauls Valley dialysis center. All I can remember about that first meeting was what he told me. He said, "We're going to help you," and I really believed him. We had hope for the first time since all this started.

Dr. Lucas started giving me an IV drip into my arm once a week. It made me so sick on the day I got

One wise person says they have learned that the best classroom in the world is at the feet of an elderly person.

the medicine, but by the next day I was OK. Nurses came to pack the open sores on my stomach on a regular basis, and things began to get better.

Slowly the gray, rotting flesh began to turn pink. In time, the wounds began to close. The regular trips to Oklahoma City and the care of the nurses continued for a year until it was over. It was like I was dying and then came back to life. I mean, really, that's what it was like.

Dr. Lucas said that calciphylaxis is a very rare disease. It is connected with kidney failure, but it is rare even then. He kept on seeing me at more infrequent times until he released me. I am so grateful to get my life back.

I had a wonderful chance to talk with another woman who had been recently diagnosed with the same thing I had. Her disease had not gone as far as mine.

I think I was able to help her feel better, and Bob talked with her husband. This was our way of saying thank you for our own healing. I think it was a miracle—yes, a miracle on Hammack Street. That's where we live.

Calciphylaxis or calcific uremic arteriopathy (CUA) is a fatal disease in patients due to calcification of cutaneous blood vessels. It is associated with renal failure. It is a devastating disease with a high rate of mortality and morbidity.

Sue experienced this very rare disease. If you are a person on dialysis, do not fear that this will happen in your case. It is a rare occurrence even among people who are currently on dialysis.

Americans with Disabilities Act Amendments Act of 2008

The Americans with Disabilities Act of 1990 is the legislation granting civil rights to people with disabilities in the United States. The U.S. Congress and the President felt that further legislation was required to clarify the intent of the ADA as originally passed. The following article was taken from *Exchange*, the winter 2008 edition of the newsletter from the Michigan Protection & Advocacy Service, Inc. located in Lansing, Michigan.

In September, President Bush signed into law the Americans with Disabilities Act Amendments Act. Though passed with less fanfare than the Americans with Disabilities Act (ADA) of 1990, this measure significantly restores protections for people with disabilities by broadening the definition of "qualified individual with a disability."

This has been done in two ways. First, the United States Congress has made it clear that the decision of whether an impairment substantially limits a major life activity is to be made without considering whether an individual uses a mitigating measure (e.g. eyeglasses, medications, assistive technology, or almost any other means that a person with a disability would use to mitigate or lessen the impact of

that disability.) Second, Congress clarified the definition of major life activities.

Congress specifically defined major life activities as:

Caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, and working.

The operation of a major bodily function, including but not limited to, functions of the immune system, normal cell growth, digestive, bowel, bladder, neurological, brain, respiratory, circulatory, endocrine, and reproductive functions.

If the ADA had been enforced as originally intended, this bipartisan piece of legislation may not have been necessary. As it stands, however, the ADA Amendments Act reverses holdings of the U.S. Supreme Court that restricted protections to millions of Americans.

When it was enacted in July 1990, the Americans with Disabilities Act held great promise for the fu-

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People of one newspaper contest were asked to supply alternate meanings for various words. Here is a response.

Abdicate=to give up all hope of ever having a flat stomach



Interesting Research on the Eye's Insulin Receptors

Dr. Raju Rajala is a researcher at the Dean A. McGee Eye Institute in Oklahoma City, and he has been investigating the causes of the degeneration of retina cells.

The retina is at the back of the eye and sends messages to the brain which permit us to see. Dr. Rajala brings out a visual image to aid our understanding.

He points to the graphic of a retina cell with tiny portals which permit the absorption of insulin into the cell. The portal is called the insulin receptor, and it is very important to the survival of that cell.

We do not know the actual function of insulin in the retina cell at this time, but we do know that if the insulin receptors do not work that glucose builds up outside the cell wall and overcomes its border. The cell dies.

Dr. Rajala is working on compounds which will permit the insulin receptors to function properly

and allow the cell wall to remain in tact. He has a promising chemical compound now which will stimulate the insulin receptors in vitro (within a petree dish).

The next stage of this research will use animal models. With success in animals, human trials will occur. So how is this research related to people with disabilities?

People lose their sight because the insulin receptors do not work. We become blind. If we could develop a drug to make the insulin receptors work in people, we might be able to save vision which is now being lost.

But developing a drug for human use could be fifteen years off. In the meantime it is nice to know that we have someone right here in Oklahoma who is studying these critical insulin receptors and has done some promising research.

Can you name three consecutive days without using the words Monday, Tuesday, Wednesday, Thursday, Friday, Saturday, or Sunday?



(answer: yesterday, today, and tomorrow)

**OFFICE OF DISABILITY CONCERNS
ANNOUNCES:
STATE OF OKLAHOMA
DEPARTMENT OF REHABILITATION SERVICES
AND
OKLAHOMA REHABILITATION COUNCIL
PUBLIC HEARING
DRS POLICY**



THE DEPARTMENT OF REHABILITATION SERVICES WILL HOLD A PUBLIC HEARING TO RECEIVE COMMENTS ON PROPOSED AMENDMENTS TO THE DEPARTMENT'S RULES. (See back of flyer for those that may affect cases with Department of Rehabilitation.)

PUBLIC HEARINGS WILL BE HELD

**MONDAY, FEBRUARY 2, 2009
4:00 P.M. — 6:00 P.M.**

**DEPARTMENT OF REHABILITATION SERVICES
2ND FLOOR CONFERENCE ROOM
3535 N.W. 58TH
OKLAHOMA CITY, OKLAHOMA**

**TUESDAY, FEBRUARY 3, 2009
1:00 P.M. — 3:00 P.M.**

**TOTAL SOURCE FOR HEARING LOSS AND ACCESS
8740 E. 11TH, CONFERENCE ROOM
TULSA, OKLAHOMA**

**WEDNESDAY, FEBRUARY 4, 2009
1:00 P.M. — 3:00 P.M.**

**GREAT PLAINS TECHNICAL CENTER
4500 S.W. LEE BLVD., BLDG 300, ROOM 301A
LAWTON, OKLAHOMA**

People with Disabilities are encouraged to come and present public comments on these proposed changes. If you would like to comment but are unable to attend, written comments may be sent to the attention of Ray Leard, Policy Development, Department of Rehabilitation Services, 3535 N.W. 58th, Suite 500, Oklahoma City, Oklahoma City, Oklahoma 73112. Written Comments must be received no later than February 4, 2009.

612:10-7-233 Special consideration in state government employment for persons with severe disabilities.

The subject of this policy was formerly known as HB1340. It is now called Optional Hiring Program for Applicants with Disabilities for state employment. It provides clarification on procedures to be followed by VR/VS counselors when approving an application for this program.

612:10-7-4 Basic eligibility Requirements for Vocational Rehabilitation Services

The intent of this policy removes barriers for individuals with the disability of alcohol or drug addiction.

612:10-7-62 Post Employment Services

The intent of this policy removes barriers for former clients to receive post employment services, by no longer tying services to the original IPE and financial status.

612:10-7-87 Actions Requiring Supervisor's Approval (Multiple Unsuccessful Case Closures)

The intent of this policy is to insure that the client has a better chance at succeeding. It requires supervisor approval to encourage steps are taken for a successful employment outcome.

612:10-7-131 Transportation (Mileage and Vehicle Repairs)

The intent of this policy is to create a formula that will calculate transportation allowance in an equitable manner to meet the client's needs. This policy will also allow for limited vehicle repairs if there is a clearly defined need for participation in vocational rehabilitation services.

612:10-7-152 Payment of tuition and fees at college and universities

The intent of this policy is to clarify application of the Pell Grant and all other Federal /State aid (excluding merit awards) in order to be in compliance with the Rehabilitation Act by applying those funds first for educational expenses.

612:10-7-219 Purchase of Motor Vehicle (Modification)

This policy allows DRS to assist with the cost attributable to the existing accessibility modifications on a new or used vehicle.

Americans with Disabilities Act Amendments Act of 2008 (continued)

ture. It was one of the most comprehensive and sweeping pieces of legislation to pass Congress in years. Over 40 million Americans with disabilities had the hope of being fully included in society and having the remedies needed to address the discrimination they faced on a daily basis.

The ADA mandated changes in employment, housing, education, governmental services, and public accommodations. It not only banned discrimination but it required that employers and others provide people with disabilities reasonable accommodations to allow them to work and participate fully in the community of their choice.

When it was enacted, many disability law specialists thought the issue that would be most heavily litigated in the courts was whether a particular accommodation was a "reasonable accommodation" or whether it posed an "undue hardship" to employers. This is because those terms are essentially undefined in the law.

However, what proved to be the most highly contested issue in the court was the very issue of who could qualify as an "individual with a disability" and be entitled to the protections of the ADA. As enacted, the ADA defined a person with a disability to be: a person who has a physical or mental impairment that substantially limits one or more life activities.

This seemingly straight-forward definition was meant to include virtually all individuals with disabilities whose lives had been affected by a physical or mental impairment. Unfortunately, the United States Supreme Court removed millions of Americans from the protections of the ADA. They did so by issuing two decisions that many disability law specialists felt unjustifiably narrowed the definition of "individual with a disability."

In the first decision, *Sutton V. United Air Lines*, a 1999 decision, the Court held that an individual could not be considered to have a physical or mental impairment if he/she had "mitigated" the impact

of that disability. A mitigating measure could include eyeglasses, medications, assistive technology, or almost any other means that a person with a disability would use to mitigate or lessen the impact of that disability. For example, if people with diabetes control the effect of that condition through the use of insulin, they would probably not be considered to have a disability, even if they were subjected to discriminatory treatment in the workplace due to diabetes. The ADA Amendments Act overturns this decision.

In the second decision, the United States Supreme Court in the 2002 case of *Toyota Motors v. Williams* held that the requirement that impairment substantially limit one or more major life activities actually meant that the impairment must significantly restrict activities that are of central importance to most people's lives. Many individuals with disabilities who had suffered discrimination were challenged to show that the way in which their impairment limited them was of central importance to most people's lives. This created an argument for employers and other entities to argue that the way in which a particular individual was limited by his or her impairment was not of central importance to most people's lives. The ADA Amendments Act overturns this decision as well.

Congress also clarified, through the passage of the ADA Amendments Act, that people who experience impairments with an actual or expected duration of six months or less, are not considered to be individuals with disabilities.

These changes go into effect on January 1, 2009. If you have experienced discrimination on the basis of your disability in the past but have been unable to obtain relief from the courts or administrative agencies, your employer, or public or private provider of goods and services because they determined that you did not have a disability, you should strongly consider asserting your rights again (after January 1, 2009 when the law goes into effect).

Advocating in Ada, Oklahoma (continued)

accessible parking places in 1996, but on-street parking was non-existent for people with disabilities.

Charlie asked that accessible parking places be designated on the street in each city block and that some of these parking places be designated for van accessibility with proper hatch marks to provide space for a wheelchair lift to unload.

In 2002 Mississippi Street which goes by East Central University in Ada was re-paved, and this provided another opportunity for advocacy. City officials told Charlie that it was the responsibility of the Oklahoma Department of Transportation to make the curb cuts he asked for, but when he called ODOT he was assured that he was correct in thinking it was the city's job.

Charlie approached the City again and was successful in getting accessibility to people with disabilities factored into city projects. It was also during this time that the Ada City Attorney changed the city parking ordinance to reflect the new Oklahoma standards of a \$150 to \$250 ticket for parking illegally in accessible parking.

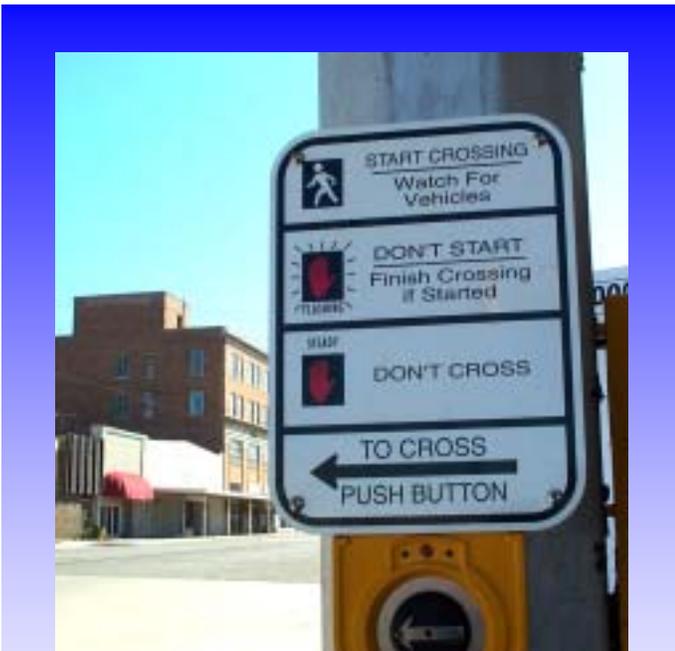
In 2006 Charlie pointed out that in the renovation of the area west of the railroad tracks on Main Street, the City had put in a new accessible parking place but had put it directly in front of the curb cut they had constructed. People with disabilities could park, but in the process they blocked their own access route to the curb cut.

Today downtown Ada has many attractions to people with disabilities which it did not have twelve years ago. The City got a grant from the Oklahoma Department of Transportation to place signal changers at all four intersections of Broadway and Main Street.

When a person with visual disabilities pushes a button on the pole at the intersection, a voice tells the person how many seconds they have before the light turns green. This is a nice thing to know if you are a person with visual disabilities. It's also nice to know if you do not have visual disabilities and just happen to be a little slow in crossing the street. Everybody benefits from things that make for accessibility.

On 10th Street and Broadway, the City of Ada had installed hand rails in conjunction with the curb cuts. Those hand rails and curb cuts actually make the intersection safer for everyone.

Many curb cuts have raised bumps on the cuts which let a person who is blind and traveling with a cane know that they are approaching an intersection. The small, rounded bumps do not provide an obstacle to other people, but they do make the way safer to people with visual impairments.



“When a person with visual disabilities pushes a button on the pole at the intersection, a voice tells the person how many seconds they have before the light turns green. “

(Continued on page 7)

Advocating in Ada, Oklahoma (continued)

Some downtown Ada street corners actually have wrap-around curb cuts which blend the sidewalk more naturally into the street. It's wonderful for everyone. Families with baby carriages don't have to compete with other people using one narrow curb cut. People without physical disabilities benefit from not having to step up to the curb.

Charlie Jones has a vision for downtown Ada. He sees increased accessibility for people with disabilities all over downtown as promoting business in his community. People take their business where they feel comfortable and where they feel they are welcome. It makes sense.

Good advocacy shares many common denominators. Charlie was aware of the Americans with Disabilities Act and knew his rights as an individual with a disability. Considerable effort was done in identifying decision-makers who could rectify the situation. He persisted in his efforts over a period of years, never giving up. In conclusion, he demonstrated a positive attitude which made it more difficult for the decision-makers to dismiss him and his advocacy without consideration. We talk about all these things in our new agency publication *The Little Book of Advocacy*. Call us at 800-522-8224 to get your copy or download it from our website at www.odc.ok.gov.

Who Knew?

An Arm and A Leg

In George Washington's day, there were no cameras. One's image was either sculpted or painted. Prices charged by painters were not based on how many people were to be painted, but by how many limbs were painted. Arms and legs are "limbs" therefore painting them would cost the buyer more. Hence the expression "Okay, but it'll cost you an arm and a leg."

People of one newspaper contest were asked to supply alternate meanings for various words. Here is a response.

Coffee=a person who is coughed upon



CALENDAR OF EVENTS

- February 11-13, 2009** 2nd Annual Combined Mental Health, Prevention & Substance Abuse Conference at the Embassy Suites Hotel and Convention Center in Norman, Oklahoma. Call 405-522-8300 for more information.
- February 19, 2009** The Alliance for Public Transportation will hold its quarterly membership meeting in Oklahoma City at a time and place to be announced. Call 405-522-6698 for more information.
- March 2-3, 2009** The Oklahoma Governor's Conference on Developmental Disabilities will take place at the Renaissance Hotel in Tulsa, Oklahoma. Contact Sheree Powell at 405-521-4972 for more information.
- March 7, 2009** "Reaching Across the Plain" Statewide Down Syndrome Conference will take place at the Moore Norman Technology Center, South Penn Campus in Oklahoma City. For more information visit conferenceinfor@dsaco.org.

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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