

WILL'S CORNER, OKLAHOMA



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(Serving the Disability Community of Oklahoma)

Share4Life

This was the title of the article on page two of the premier edition of *Will's Corner, Oklahoma* written way back in May of 2000. I remember going down to Purcell, Oklahoma to interview Linda Durbin, and that early article had a nice picture of Linda at her work station where she refurbishes donated computers to give to people with disabilities all over Oklahoma.

One of the callout boxes in that article informed that the AMBUCS Share4Life Komputers (ASK) of the civic organization Sooner AMBUCS in Norman had placed 550 computers in homes of people with disabilities. It was an exciting day and a learning experience for a new Disability Program Specialist who still knew very little of the resources in Oklahoma to assist peo-

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Cancer Research

What if we could discover a particular substance produced by the human body which occurs simultaneously with the spread of some of the leading kinds of cancer? What if we could then find some kind of chemical compound which would deactivate that particular substance? Would this prevent or retard the spread of the cancer? Maybe.

Dr. Thomas Pento at the Department of Pharmaceutical Sciences at the O.U. Health Sciences Center in Oklahoma City is researching just such a thing right now. He has located a substance more easily referred to as KGF which is produced by the human body naturally and appears to be connected with the spread of cancer cells from their tumor of origin to other parts of the body.

Dr. Pento is hoping to locate a chemical compound which will prevent the KGF from stimulating cancer growth in particular kinds of cancer. KGF appears to be activated in the spread of some of the leading kinds of cancer such as cancer of the breast, the prostate, colon and lung. Dr. Pento is researching 40 chemical compounds with a comrade from Ohio State University which have the potential to inhibit KGF.

He shows me a poster with the picture of three mice who have been injected with cancer cells, and small tumors are clearly visible beneath the skin. He shows me these same mice with their tumors after receiving KGF. The tumors have quadrupled in size. The thinking is that if KGF can be deactivated, cancer tumors can be contained before they spread. Then they could be easily removed by surgery.

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OHC web site:

www.ohc.state.ok.us

Cancer Research (continued)

KGF became a suspect in the cancer scene ten years ago. In 2001 an article published in a professional journal demonstrated that KGF actually stimulated the movement of breast cancer cells. A paper was published in 2006 further implicating KGF in the spread of cancer cells of some of the leading kinds of the disease.

If KGF could be “turned off” with some kind of drug, we would have a new approach developed in the treatment of some kinds of cancer. Today most of our chemotherapy to control the spread of cancer is non specific. That is, the treatment is a shotgun approach aimed at retarding the replication of any rapidly dividing cells in the body.

The problem with this approach is that the chemotherapy kills healthy cells in the body as well as cancerous cells. Hair follicles are cells which divide rapidly in the body, and they are not cancerous. That is the reason that people undergoing chemotherapy experience the loss of their hair. The chemicals affect all cells that divide rapidly whether they are healthy cells or not.

If Dr. Pento could locate a compound to block the production of KGF, this approach would specifically target cancer cells. That is one major difference in this new approach. Dr. Pento explains that some women have a genetic predisposition to develop breast cancer. If a compound could be located to block the effects of KGF, these women might take this as a preventative to make sure they did not develop the disease. Intriguing.

All cancer cells are not the same. The cells are different and attack different areas of the body. While KGF is present and “turned on” in the spread of several of the most common kinds of cancer, it is not “turned on” in all types of cancer. Dr. Pento says, “We may cure cancer some day, but there will not be one single bullet to cure cancer because there are so many kinds.”

The research currently being done at the Department of Pharmaceutical Sciences may lead to better

...this approach would specifically target cancer cells...



cancer drugs which have strong possibilities for making it to market. The research being done now uses animal models. Before pharmaceutical companies act on the present research, human studies will probably have to be done. Human studies can be conducted at a cancer research center of which there are about 50 in the United States. For about five years we have had a cancer research center right here in Oklahoma City.

If everything went just right, we could actually have an FDA-approved drug based on Dr. Pento's initial research in ten years. (That time frame presumes many things.) Most of us welcome any kind of tool to fight this disease which is one of the leading causes of death in the United States.

It is exciting that cancer research such as this is being done right here in Oklahoma. Dr. Pento has received funds from the National Institutes of Health, the U.S. Department of Defense, the Presbyterian Health Foundation and the Oklahoma Center for the Advancement of Science and Technology. He has also received some funding from the American Cancer Society. Some of these funding resources are based within our state.

Dr. Pento shares another line of research in addition to the research on KGF. He tells me that the Human Genome Project was completed in the year 2000 which has mapped out the 30,000 genes present in the human body. Scientists have been able to map these genes on a chart and locate those genes most affected when particular types of cancer are present. Some day we may be able to do “gene therapy” to reduce genetic predisposition to cancer. These kinds of research appear to offer promise that we are making progress in controlling this disease which has brought so much suffering to our world.

Adoptions of OKDHS Custody Children

Today there are about 12,000 children in the custody of the Oklahoma Department of Human Services. Some of those children have special needs. All of those children are seeking adoptive homes where they can experience love, nurture and an atmosphere where they may develop their natural abilities to the maximum.

Karen Poteet is the Programs Manager of Adoption Assistance and Post Adoptive Services for OKDHS. Her job is to help secure and support safe and permanent adoptive families for children with special needs which will fulfill each of their needs as well as create a better social environment for all in our state. That's a tall order.

Fortunately she has been given some tools to work with. There are incentives built into the system to encourage Oklahomans which may have been thinking about adopting a child who is in the custody of our state.

Children adopted through OKDHS will receive automatic medical coverage through Oklahoma Medicaid. This insures that the child being adopted can have health coverage which can be a big issue for children who have special needs.

Children bring with them to their potential adoptive homes a monthly stipend to assist families in the cost of raising another child. OKDHS may also assist Oklahoma families adopting children in custody by paying for certain one-time expenses such as the legal costs of adoption itself.

Karen Poteet also shares that for a family or single individual adopting a custody child over sixteen years and nine months old, that child can receive a full tuition waiver at any Oklahoma college or university. Karen explains that parents adopting older children may not have saved for the higher education of this child, and this brings a real incentive to invest in their child's future.

Today Oklahoma has over 9000 children which have been adopted into over 5000 homes across the

state. These figures compare favorably with the 12,000 custody children, some of whom are looking for adoptive homes.

One reason we are having a greater movement of children out of foster care and into adoptive homes is the federal 1997 Adoption and Safe Families Act. This law placed time frames on the length of time a child can spend in foster care as well as provided financial incentives for states to focus more attention on adoption. This law has revolutionized the foster care system nationwide by promoting adoption.

In 1999 Oklahoma created a whole unit in OKDHS called Swift Adoptions to facilitate movement of children from foster care to adoptive homes. Partly because of these efforts, Oklahoma has placed more custody children in adoptive homes than any other state in the nation per capita.

When you adopt a child in OKDHS custody, that is not the end of the state's involvement. Oklahoma recognizes that married couples and single adoptive parents welcome support to help them meet the needs of their new children. Twice a year OKDHS sponsors retreats for adoptive parents to assist them in coming up with good parenting solutions. Child care is furnished while parents are on retreat.

OKDHS also provides a helpline to assist adoptive parents with information and referral of services in their local area of the state. In addition, adoptive parents may qualify for respite care through the Oklahoma Respite Resource Network. These

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State of Oklahoma

web site:

www.ok.gov

Raymond's Room, a Book Review

Dale DiLeo, author of *Raymond's Room: Ending the Segregation of People with Disabilities* offers readers some condensed insights into people with developmental disabilities which will challenge them to put away their pre-conceived ideas and take a fresh look. Mr. DiLeo takes off the blinders and brings his readers intimately into his experiences with people with disabilities over a long career. His understanding of and empathy with people with disabilities breathes passion into his case for tearing down attitudinal barriers which have in themselves limited people with disabilities for generations.

Raymond's Room was a real place well-hidden from public view inside a residential facility for children with autism. This room was not much larger than a walk-in closet and was used to house children with "problem" behaviors. The stench from a room locked from the outside with a portable toilet inside was overwhelming. This room was referred to by staff as *Raymond's Room* because Raymond was the room's most permanent resident.

From this backdrop and inside view of how we housed and cared for people with disabilities in 1975, the author takes his readers through the looking glass of time down to the present to give us an historical perspective. We also look at the broad picture of all aspects of life for people with disabilities including home, work and play.

Mr. DiLeo spends a chapter looking at challenging behaviors which people with disabilities may exhibit in their efforts to be heard. Not only does he dispute some of the older, physically-punishing responses to challenging behaviors, he also points out where some of the more modern methods to control behavior may fail to address the real communication which the client with disabilities may be trying to express. He suggests that staff establish trust with clients before attempting to mold the behaviors which staff deem inappropriate.

Raymond's Room takes a big step in correcting myths which the general public has about people

***Raymond's Room* reminds us all that people with disabilities have the same needs as everyone.**

with developmental disabilities. But, it goes much further than this. It illustrates how those of us in the service-delivery system unwittingly perpetuate some of these same myths in spite of feeling that we are more enlightened than some in the general public.

The current slogan of "people first" is a common theme woven throughout the book. There is little doubt that many of us when we perceive an individual with disabilities tend to first look at the disability before we see the common humanity that we all have. This is a lesson for all of us—even many people who work with people with disabilities.

Mr. DiLeo coins a new phrase—the disability industrial complex. This phrase seems to be a take-off on an older term referring to the military-industrial complex which was used to describe American society from the 1960's to the present. Many who used the second term were referring to a crushing "system" where the individual's needs were overlooked in order to perpetuate a system for its own sake.

The author seems to suggest that those of us in the disability field have also created a system which perpetuates itself rather than serving those for whom it was intended. Social service agencies are challenged to look at their policies to insure that we are building our policies to serve rather than to control. This book will prompt some serious introspection.

Raymond's Room reminds us all that people with disabilities have the same needs as everyone. They value privacy, accomplishment and interdependence. In short, they want a place in society just like

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Raymond's Room, a Book Review (continued)

everybody else. After our struggles with segregation when it referred to people of color, it appears we can take a further step in application of what we have learned to people with disabilities.

Learning to truly listen to people with disabilities is an acquired skill. Sometimes we continue to look at people with developmental disabilities as having deficits which it is our duty to "fix". We identify the deficit, and we decide how to correct these so-called deficits. Somewhere in this process, we may lose touch with what the person with disabilities wants. We are challenged to change some of our very basic attitudes which we may not even be totally aware exist.

What binds us to other people? What creates a sense of community? Mr. DiLeo points out that we have identities as belonging to certain groups. We may be a parent. We may be a voter. We may have an identity as doing a certain type of work. We may belong to a particular organization. Most of us have an identity in various groups, and the sum of all these identities defines who we are and how we fit into our community. People with disabilities are much more than the disability which we have.

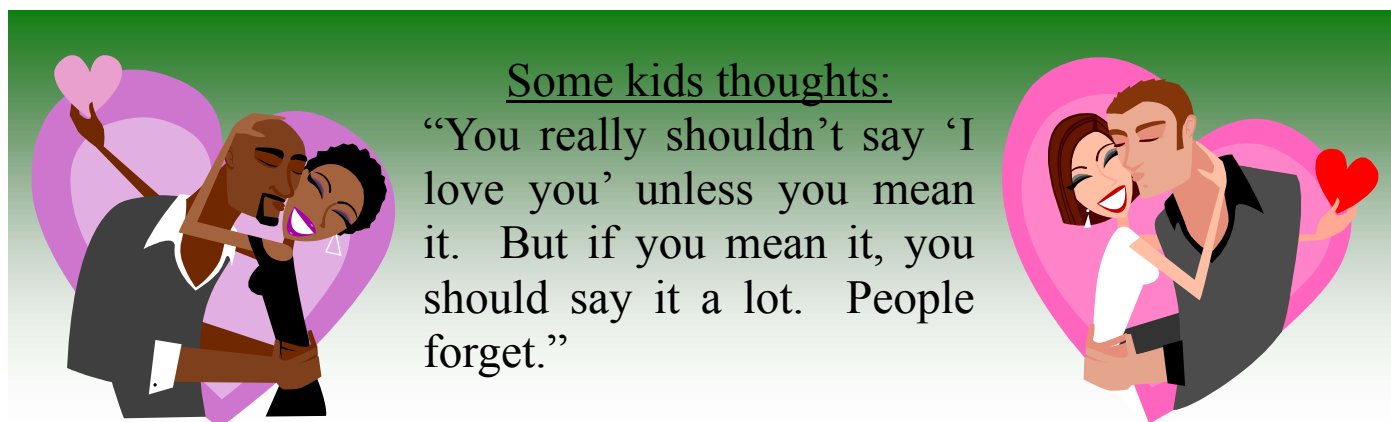
Some of us are democrats, republicans, or independents. We come with various colors to our skin. We may be an auto mechanic, a cashier or a pediatrician. We are multi-faceted, and as people identify with us because they have a similar interest, a bond forms between us. We are connected. We do

people with disabilities a service when we help them discover who they are in the broader world out there.

Mr. DiLeo emphatically reminds his readers of the importance of having a job which matches the interests and abilities of people with disabilities. Of course this is important to all people, regardless of ability. Workshops for people with developmental disabilities do not match people with a job which reflects their interests and abilities. The author objects to the use of workshops to serve people with developmental disabilities on the same basis he has used to object in every arena of life. They are segregated facilities which are separate but not equal.

Does this book talk about people with developmental disabilities, or does it talk about people with disabilities in general? I think the answer to that question is both. Is Mr. DiLeo qualified to write about the services of people with disabilities? I think the answer to that question is yes. He has worked directly with individuals with developmental disabilities. He has taught special education. He has been a director of an agency. He has been a consultant for agencies working with people with disabilities. He has worked in a broad spectrum of capacities.

***Raymond's Room* has a 2007 copyright by Training Resource Network, Inc. in St. Augustine, Florida. Its 212 pages read fast. For those of you interested in further reading, it comes with lots of references to other professional works. It may or may not be in your local lending library.**



Share4Life (continued)

ple with disabilities in meeting their needs.

So where are we going with this? I met Adri-Anne Trammell again at a recent meeting and asked her how things were going. Sooner AMBUCS seems to be making some big strides forward, and I wanted to let you know about what's going on down there.

AMBUCS is a civic organization with 135 clubs nationwide and about 35 in the Oklahoma/Kansas region. AMBUCS has chosen to work projects involving people with disabilities. I learned when gathering information for this article that many of the chapters build ramps for people with disabilities. They also provide therapeutic tricycles and scholarships for individuals studying to be physical, occupational, and speech and hearing specialists.

The Norman chapter of AMBUCS has chosen to refurbish donated computers and give them away to people with disabilities. Adri-Anne Trammell tells me that currently they are the only AMBUCS chapter doing this project although others have expressed interest. Adri-Anne Trammell is the Project Manager of the ASK Project for Sooner AMBUCS, and Linda Durbin does most of the repair work on the donated computers.

As I said, there is a lot going on now at Sooner AMBUCS. On Saturday February 24, I attended their open house at their new 5000 sq. foot offices in Norman. On October 8, 2006 they received a \$195,650 grant from the U.S. Department of Education for the purpose of reutilizing assistive technology for people with disabilities. Sooner AMBUCS was one of only ten organizations in the United States to receive one of these special grants.

On top of renting the new space, Sooner AMBUCS has bought an 18-foot box truck and employed some part-time employees to help them at their new offices. This has been a big expansion for this private, non-profit agency. Adri-Anne speaks glowingly of the bathroom facilities which they have in their new offices. That spoke volumes to me about



Linda Durbin on the left and Adri-Anne Trammell on the right. The center figure remains unnamed.

...they have given away 4500 refurbished computers ...

what kind of office space they had before. I don't even want to ask.

Some of the computers which they refurbish come with access to the Internet and some do not depending on the needs of the person receiving the computer. Generally speaking, if you need JAWS to read your computer screen or if you need voice recognition software, you will need to purchase those programs on your own. AMBUCS will provide a computer capable of running that software.

Sooner AMBUCS refurbishes donated computers, but they will accept models only so old. They proudly share that as of Saturday February 24, 2007, they have given away 4500 refurbished computers to people with disabilities throughout the state of Oklahoma!

Sooner AMBUCS Share4Life Computers gives

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Share4Life (continued)

computers away to people with disabilities. They do not, however, deliver the computers. Adri-Anne explains that they like to give a demonstration of the computer they are giving away and that they prefer if the person with disabilities or their representative can come to get a demonstration when they come to get their computer.

The computers have been wonderful for adults and children with disabilities. Many people have used their donated computer to open up a home business. One man, a sculptor, stated his intention of using the computer given him to sell his art work. He was no longer able to work outside his home and wanted to establish a home business. One woman who had been a quadriplegic for 20 years states her intention of using her computer to complete her education.

Many computers are equipped with software to help children learn through a variety of educational games and programs. Children with developmental disabilities frequently use donated computers to teach them their colors, shapes, and telling time so these children will be prepared to enter public school.

Right now there is a waiting list of 60 people to get a donated computer. Adri-Anne states that this waiting list is about a month for a low-end computer and three months for one of the other models.

The new address of Sooner AMBUCS is 2012 Research Park Boulevard in Norman. This is near where Flood intersects Rock Creek Road. You may contact Adri-Anne Trammell at 405-360-1521 or Adri-Anne@cox.net. Sooner AMBUCS website is www.soonerambucs.org.

Sooner AMBUCS is always looking for volunteers to help them unload computers or pick up donated equipment. Of course they are always looking for support from the business community in the form of donated computers and financial support for the project. Sooner AMBUCS is a 501 (c)(3) organization, and your donations are tax deductible.

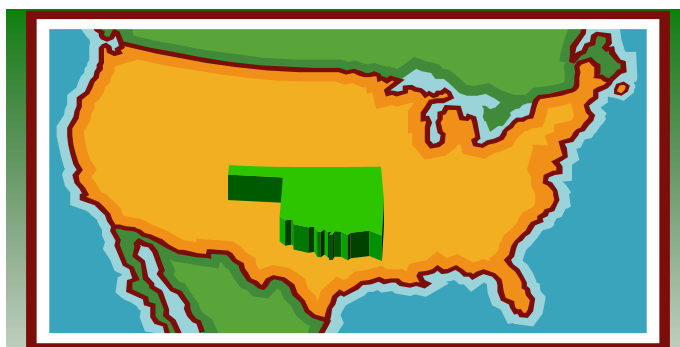
Adoptions of OKDHS Custody Children (continued)

things are all part of what are called post-adoption services for families and singles who adopt through OKDHS.

When asked about her vision for the future for adoptions, Karen says she would like to have a post-adoption worker in each of the six OKDHS regions of the state so they could provide even more hands-on assistance to couples and singles. Parents want assistance in locating services for their adoptive children.

At the end of our interview, Karen Poteet tells me they also provide assistance to adults who were adopted in Oklahoma to locate siblings and birth parents. Most recently a sister was reunited with two brothers after fifty-six years of living apart across half a continent.

If you are interested in finding out more about adopting a child in the custody of the Department of Human Services, call toll free 877-657-9438. You may request some special publications like *Oklahoma Adoption Assistance Program* (OKDHS pub. #91-26), *Swift Adoptions* (OKDHS pub. #00-29) and *Permanent Connections* (OKDHS pub. #13-18.)



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CALENDAR OF EVENTS

May 8-10, 2007

The Aging Services Division of OKDHS is sponsoring the 2007 Conference on Aging at the Reed Center in Midwest City. The conference is free to people 60+ for Wednesday, May 9. For information on cost the other days and registration, call 405-521-2281.

May 19, 2007

The Oklahoma chapter of the National Association of Mental Illness will be holding their Annual Walk in Oklahoma City. For more information call 405-230-1900 in central Oklahoma or 800-583-1264 statewide.

June 7-10, 2007

The University of Central Oklahoma is sponsoring the 8th Annual endeavor Games for athletes with physical disabilities. For more information call Katrina Shaklee at 405-974-3144 or email kshaklee1@ucok.edu.

June 14-16, 2007

The Oklahoma Association of the Deaf will be hosting their statewide conference at the Tulsa Community College-Northeast Campus. For cost and registration contact Glenna Cooper at 800-697-9445.

June 21-24, 2007

The Oklahoma City chapter of the Hearing Loss Association of America will sponsor the national convention in Oklahoma City at the Renaissance Hotel and Cox Convention Center. For more information call 405-951-8383 or go to <http://www.okc-hearingloss.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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