



Wings

...Those who wait upon the LORD shall renew their strength, they shall mount up with wings like eagles, they shall run and not be weary, they shall walk and not faint. Isaiah 40:31 [NRSV]

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For, By and About PHUMPS
(Physically Handicapped United Methodist Persons)



Fall
1996

FROM WHERE I SIT

By Jo D'Archangelis

**THOU
SHALT
ENTER**

[Note: The following is a greatly expanded and modified-almost-to-the-point-of-non-recognizability version of remarks made by yours truly at an Access Sunday observance at Fallbrook United Methodist Church, Sept. 25, 1995.]

For our annual Access Sunday observance, our pastor asked me to say a few words on what Access Sunday meant to me as a disabled person. So I thought and I thought and I thought and...came up with very little that was particularly fresh and/or inspirational.

I could have pointed out the many and various ways Fallbrook UMC had been made accessible to persons with disabling conditions. I could have expressed my appreciation for the ramped and/or leveled entrances to 90% of the church facilities, for the large print worship bulletins, for the amplification sound system for the hard-of-hearing members, for the accessible restrooms, for the handicapped parking spaces—none of which the church is legally required to provide.

But I had already been duly and sincerely grateful in talks given previously, and I wanted to deviate somewhat from the notion of accessibility as a special gift to 'special' people. To me the more pertinent issue at hand was what Access Sunday meant to any of us in the church, whether disabled or non-disabled.

Is Access Sunday a time to recognize the talents, abilities, and gifts of disabled people within the church and to commit ourselves to utilizing them throughout the year? Or is it a time to thrust the disabled people in our churches into the limelight for an hour or so and then forget them the rest of the year?

Is it a time to honestly assess the level of accessibility of our churches—physical, theological, and attitudinal—and to re-commit ourselves to achieving a higher level in the future? Or is it a time to congratulate ourselves

on our ramps to the sanctuary door and smugly conclude that we don't need to do anything more?

Of course, Access Sunday should be a time of recognition, re-assessment, and commitment on all our parts to making the church accessible to everyone. But it seemed to me that that wasn't all there was to it.

Why, I wondered rhetorically (rhetorical wondering being one of my favorite pastimes), should the

Why...should the church be made accessible in the first place?

church be made accessible in the first place? Because the church in Christian charity bends down to us poor disabled folk and bids us enter so that it may care for us in our need? Or because we, the so-called marginalized of society, batter on the doors of the church demanding our just and full right to enter and to be treated with equality?

Or is it because without the full inclusion of those whom the world looks on at best as objects of

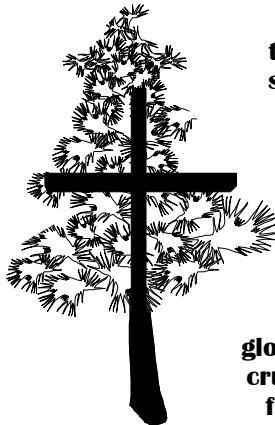
sympathy or pity or at worst as objects of embarrassment or even revulsion—but whom God looks on as his children pure and simple—the church becomes sadly lacking in its God-ordained mission to 'make disciples' of all peoples and in its ministry of wholeness and healing?

Dr. Ken Tittle, founder/co-director of Mariposa Ministry, puts it about as well as anybody could when he writes in *In All Things* that "God longs for the body of Christ, which is his church, to include fully all sorts and conditions of humankind, each of us glorifying and serving God in our unique situations and our corporate unity. The church needs the ministry of persons with disabling conditions."*

Indeed, the church needs the ministry of persons of any and every condition. Accessibility is the necessary means by which and the sustaining environment in which we, disabled and non-disabled alike, learn to support and to bless each other and to work together for the realization of God's kingdom on earth.

*See *In All Things* reprinted in full on page 4.

SEQUOIAS



**tall, huge, majestic, strong
scarred by lightning but still living and growing
down through the years
up through the years**

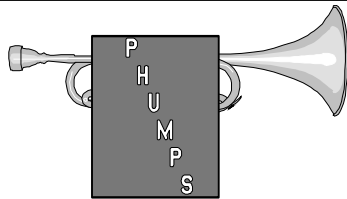
**big trees teach us little people
to live and grow and be strong
in spite of scars
because of scars**

**glorious, faithful, perfect
crucified but still living
from years past
through all eternity**

**jesus teaches us helpless people
to live and pray and have faith
in spite of our sins
because of our sins**

- Janine Noel Wickers -
April 24, 1996

Wickers, who has multiple sclerosis, lives in Cypress, Calif., and is a member of St. Mark's United Methodist Church in Anaheim, Calif.



ACTS AND REVELATIONS: FROM AND ABOUT OUR READERS

'Access Unlimited' is the new name of the Los Angeles radio program hosted for the past several years by **Martha Griswold** over KPFK [90.7 FM]. The name was suggested by a couple of listeners in "a bit of a contest", says Martha, who is Executive Director of the Living Independently in the Valley Center, Altadena, Calif. 'Access Unlimited' can be heard every Friday at 2:30 PM...

Richard Daggett, President of the Polio Survivors Association of Los Angeles County, has been getting more than his share of 15 minutes of celebrity this year. First he was featured in the *New Mobility* April issue on Post-Polio Syndrome. Then in August on the PBS affiliate in Los Angeles, he co-hosted a documentary on Rancho Los Amigos Medical Center in Downey, Calif. Richard spent several months at Rancho in an 'iron lung' after contracting polio in 1953...

Kudos [no, not the granola bar] to **Dr. Kenneth Tittle** and **Lupita Alonso de Redondo**, co-directors of the Mariposa Ministry in Calexico, Calif., who were honored as Layman and Laywoman of the Year this past June at the California-Pacific Annual Conference of the United Methodist Church. Mariposa, founded by Dr. Tittle more than 20 years ago, is a Christian-based peer-counseling group of mostly young adults with long term physical disabilities...

How Will They Know If I'm Dead? Transcending Disability and Terminal Illness is the intriguing title of a book by **Robert C. Horn** to be published by St. Lucie Press at the end of October. Bob, an active member of the United Methodist Church in Northridge, Calif., was diagnosed with ALS in 1988. Using his right foot [the only moving part of his body] and a computer, he wrote the book at the rate of one page every two days. If the book synopsis is any guide, *How Will They Know...?* promises to be a remarkably well-written paean to life and all its possibilities. It will be available at Barnes and Noble and B. Dalton bookstores.



**PSSSST--
WANNA BE AN ANGEL?**

For some time we have wanted to expand the distribution of *Wings* to United Methodist Conferences outside the California-Pacific Annual Conference, where most of our readership is currently located. To do this, increased resources will be needed. Annual sponsorships seem to us to be the best way to go at this time to provide financial support not only for continued publication but also for reaching new readers nationwide. Sponsorships, unlike subscriptions, are not required for anyone to stay on or to be added to our mailing list. They are simply a more systematic and [we hope] effective way to encourage voluntary contributions. By the way, if you want to be dumped, you have to ask for it!

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Wannabe sponsors/angels, please make your checks payable to the Fallbrook United Methodist Church, mark them 'Wings Newsletter', and mail them to the church address or home address given at right. And thank you.



GOLF CARTS FOR CAMPERS? YES!

From a recent issue of the California-Pacific Conference newspaper, *Circuit West*:

The California-Pacific Conference "Strength for the Journey" HIV/AIDS camping program is seeking the donation of a new or used golf cart.

The Rev. Chuck Kishpaugh, Director of Operations of the Conference Board of Camping, Outdoor, and Retreat Ministries, said the cart is urgently needed to help transport campers over the sometimes rough and steep terrain of Conference campsites...

Kishpaugh said either a gasoline powered or an electric model golf cart would be greatly appreciated and put to good use transporting campers....

An ever better idea would be to have golf carts at all Conference campsites. Many disabled campers and senior-age campers also have difficulty navigating rough and hilly terrain.

If you know of an available golf cart, please contact Kishpaugh at the Conference Center, 818-568-7300.



Wings is a non-profit quarterly newsletter published by and for United Methodist adults with physically disabling conditions.

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Computer Layout/Graphic Design
Jo D'Archangelis

Wings Needs the Following From You
Ideas and suggestions for articles
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Personal essays and anecdotes
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STRONG IN GOD

By Cyndie Claypool de Neve

At first glance, Don Talley doesn't look like he would have a thriving youth ministry. But when the 6-foot, 100-pound man talks, teens listen. He can't hide his most vulnerable area, and kids, in turn, don't hide theirs.

When Talley was 7, he was diagnosed with a rare form of muscular dystrophy. The muscle fiber disease causes muscle weakness, but not deterioration, throughout his body. Full-leg braces help him walk and stand, and he frequently holds his head with his thin hands because his neck is the weakest part of his body. In the fast-paced youth culture, Talley, 29, speaks and moves slowly. Yet teens are attracted to him.

As executive director of Youth For Christ's North [San Diego] County chapter, Talley started one of the groups—geared at introducing non-Christians to the Bible—at Rancho Bernardo High four years ago. That group now averages 139 members at the weekly meetings, making it one of the largest groups of the 230 chapters nationwide.

Talley's positive attitude is obvious. "There's advantages and disadvantages. I get great parking and get to go to the front of the lines at Magic Mountain," he joked. "I'm the most popular guy when it comes to Magic Mountain trips..."

However, there are disadvantages. Physically, it's hard for him to walk without his braces, and with his braces, he walks stiff-legged. "I will fall easily," he confided. "Falling is a scary thing for me."

But Talley doesn't dwell on the negative for long. "The Lord's really good to me. The kids I work with are very careful around me." He explained that in a crowd, some kids will walk three steps behind him so he won't get bumped, while another walks in front of him so he can put his hand on his shoulder. Or they'll pick him up and carry him up the stairs. "The crazy thing is, the help is never solicited," he said with a smile.

Even though Talley grew up thinking his frailty would be problematic in working with youth, he has found the opposite to be true. "Kids want people to understand their hurts. Yet we live in a society that shuns weakness," explained the thin, blond man. "When I walk up to a kid, that kid automatically knows my most vulnerable point. I cannot hide that from them. And as a student begins to

understand and know me, it's amazing how free those kids are to share with me their honest and true hurts, their vulnerabilities. Subsequently, when you have that relationship with anyone, it's easy to get down to the core issues."

Before starting the group in North County, Talley worked behind the scenes for Campus Life in San Diego as the media director. He thought that would be as close as he'd get to working with youth... "Being limited

"I finally got to see that little boy in me... He was hurt, angry, wanted to be loved and accepted for who he was. And I realized I never embraced that part of me."

physically and growing up in a situation where relating to kids meant playing hoops, volleyball, wrestling, being as active as the kids were, I felt my input with kids would be behind the scenes," he said.

Talley had to struggle with his frailty daily, yet he never had to face it emotionally. He was the only one he knew of with muscle fiber disproportionism. He took refuge in the fact he never had to see anyone like himself, which meant he never had to address his feelings about his disorder. "I never had to face myself in the mirror or get a grasp of the value or blessing of my disability," he said.

Until he got a phone call in 1988. A woman named Pam Ferro called saying her daughter, Melissa, had

been diagnosed with the same disorder as Talley. "All of a sudden, I wasn't alone anymore," he remembered. "God was saying, 'Don, it's time for you and me to do some business. It's time to embrace your frailty and weaknesses.' It was hell."

Talley and a friend went to visit the Ferros. "Dealing with Pam was fine. I could deal with adults, no sweat. But I was terrified of that 4-year-old girl," he said. Watching Melissa maneuver around the living room, holding onto tables and couches to walk, reminded Talley of himself when he was young.

"I finally got to see that little boy in me," he said. "He was hurt, angry, wanted to be loved and accepted for who he was. And I realized I never embraced that part of me." When Melissa finally made her way over to Talley, she fell into his arms. Hugging her, Talley said, was like embracing the child in him he never wanted to acknowledge.

After visiting the Ferros, Talley stopped hiding behind his media director title and started working with the students themselves. "I opened myself up to build relationships with these kids, and I knew there was no way I could ever go back to just being the media guy," he said...

Talley said he is enjoying the position he has now. "I love training and mobilizing people to reach kids. I love being a part of kids' lives. I love the opportunity I have now to speak and affect kids from different parts of the country," he said.

Reprinted by permission of the
NORTH COUNTY TIMES
[Escondido, Calif.], July 12, 1996.



WHEELING AND WAVING, UNITED METHODIST CARRIES FLAME

By Christy Awad

Nancy Starnes knows how hot the Olympic Flame burns. She has felt it, up close and personal. Ms. Starnes, member of Sparta United Methodist Church in New Jersey, wheeled the torch on a half-mile stretch through Burson County in June as part of its 15,000-mile journey to Atlanta.

For the Torch relay, Ms. Starnes' wheelchair was equipped with an adapter which attached to the chair and left her hands free. "I was using one hand to wheel and the other to wave to the crowd," she said.

The adapter brought the flame close to her face, Ms. Starnes said, and she could feel the heat flow toward her as she wheeled forward. "It was incredible," she said.

To become a torchbearer in the Olympic relay, Ms. Starnes was nominated as a community hero and voted on by a national panel. She said she was flattered, not to mention surprised, at being chosen. Ms. Starnes, a member of the 1985-88 churchwide Hymnal Revision Committee, was recently chosen as Ms. Wheelchair New Jersey and president of the New Jersey Coalition on Women with Disabilities.

"I'm going to feel a very special connection when they light the torch in Atlanta," she said. The lighting of the torch officially opens the Olympic Games.

Reprinted from the *United Methodist Review* [July 12, 1996].

IN ALL THINGS By Kenneth M. Tittle

And we know that God works all things together for the good of those who love him and are called according to his purposes. (Romans 8:28)

Able-bodied persons tend to view persons with disabilities with a mixture of compassion and pity. Perhaps many persons with disabilities view themselves in the same way. However, Christians—that is, those of us who love [God] and are called according to his purposes—should see things differently, should we not? Surely we are called to trust that physical disabilities are included among all those things which God works together for our good...

We, too, would trust in his power to work for our good, even through things such as disabilities, which the world considers bad—trusting in the same power which transformed the shameful cross into the instrument of salvation.

God calls his church to include all believers fully in fellowship and to develop each person's God-given gifts in his service. We believe the church has failed to minister the fullness of Christ's love and healing to persons with disabilities. The lack of their free, full participation sadly diminishes the body of Christ.

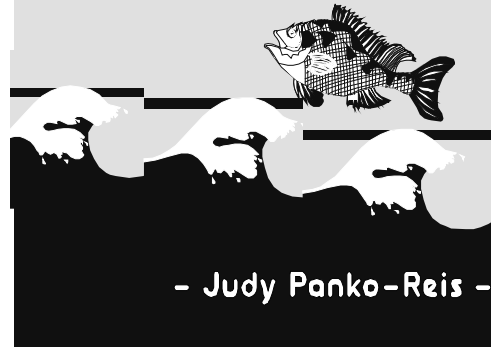
Architectural barriers such as stairs and inaccessible restrooms are important problems, but there are also attitudinal and theological barriers for persons with disabilities. Because of superficial and inadequate theological understandings of disability, affliction, and healing, the church is often ill at ease with those who suffer intractable illness or have obvious physical defects or limitations. We cannot minister God's healing and consolation in power, we are not prepared to face our own defects and limitations, and our faith may not sustain us in testing and affliction.

Scripture teaches us we are all "disabled"—limited and imperfect—in God's eyes. Neither disabilities nor weakness nor pain are necessarily "bad". In Christ we are each uniquely gifted and valuable, and God wishes to use all that we are to his honor and glory.

The body of Christ is not complete until it fully includes those persons with obvious disabilities and limitations. Together we learn to become more compassionate and effective instruments of healing for one another. Together we learn to acknowledge our limitations and needs before the Lord. Together we learn to stand firm in trials and to allow God to purify and mold us in the crucible of life. God longs for the body of Christ, which is his church, to include fully all sorts and conditions of humankind, each of us glorifying and serving God in our unique situations and our corporate unity. The church needs the ministry of persons with disabling conditions.

Reprinted by permission of Mariposa Ministry [Calexico, Calif., 1992].

**swimming upstream
against the
disabling flow
of the
status quo**



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Panko-Reis is Executive Director
of the Health Center for Women
With Disabilities in Chicago, Ill.

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