

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]

Vol. 7 Issue 4
No. 28



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



Spring
1997

FROM WHERE I SIT By Jo D'Archangelis

When Bill Clinton tripped, tore some tendons in his right knee, and wound up in a wheelchair, I silently wished him well and then thought, "How cool!"

I mean, someone so obviously vigorous and attractive, and "Leader of the Free World" yet, going about his presidential duties—settling crises, bugging Congress, eating Big Macs—and showing that it could all be done from a wheelchair. What a wonderful message it would send to disabled young people!

So what message do we get? First, while Clinton makes a game effort to summitize with Yeltsin in Helsinki, the news media report that Clinton is being delivered in a...catering truck. Well, okay, maybe bulletproof wheelchair lift-equipped vans are in short supply in Helsinki.

Then Yeltsin starts making cracks about Clinton and not him being the "ailing" one, and everybody laughs. A televised press conference at the summit's end shows Clinton in his wheelchair with Yeltsin towering over him and the news commentator remarks that Boris "looks down" on Bill.

Soon Clinton is canceling his travel plans and public appearances left and right, and *Newsweek* reports White House aides are "troubled" by the "undignified" sight of the President of the United States being "hauled in and out" of vans. Says one: "We don't want things looking too FDRish around here."

FDR? Oh yes, wasn't he the guy who had polio and served as president for nearly four terms in a wheelchair but hardly anybody knew that because he refused to let his disability be seen in public?

Columnist George Will, hardly a Democrat-lover, says this was "courageous" on FDR's part, but Will gets it completely backward. It wasn't courageous at all, but rather a timorous

capitulation to the disability-phobia of the time. And in that sense, things *are* looking "FDRish" around the White House—unfortunately.

Recently I read of a TV-movie aired a few months ago in which a young wife and mother winds up in a wheelchair with MS. She not only condones but encourages her husband to have an affair with a very, *very* able-bodied friend. I groaned inwardly: another simpering female unwomaned and made stupid by a wheelchair.

But that's television—right? Well...

A few weeks ago, in a sermon on self-denial a United Methodist minister related the story of a woman of his acquaintance, married and the mother of young children, who was diagnosed with multiple sclerosis (MS). She was put into a county institution where, after much deliberation, she decided to divorce her husband so that he could marry someone else and provide their children with a mother. (He, by the way, complied.)

The message the minister intended to send was simply that of noble sacrifice. However, the story of this particular "sacrifice" only served to reinforce the belief in the minds of

many TABs (the temporarily abled-bodied) and, yes, PWDs (persons with disabilities), that we are useless burdens who cannot function effectively as husbands, wives, or parents and that, for the sake of our families, we ought to crawl onto an ice floe and head out to open sea.

For me personally the implicit message was that this woman had tragically succumbed to the dubious notions that motherhood means being able to change diapers and wifehood to vacuum the carpet and dance the two-step. Apparently there was no one to tell her that within and from her physical limitations she had even more valuable and irreplaceable gifts to give to her husband and children.

Clinton now says that he understands what it's like to be disabled, a pronouncement that some disability leaders have praised. Yeah, right. I'm afraid that what he understands is that presidents in wheelchairs are looked on as undignified, sick, weak, unmanly, unattractive, ineffectual, and very short.

I'm glad Clinton seems to be recovering more quickly than expected and no longer needs a wheelchair. Too many more of these wonderful messages we're getting about ourselves and disability and we'll all be calling Jack Kevorkian.



EARL MILLER SPIRITUAL LIFE RETREAT —SEE REGISTRATION FORM INSIDE!—

FOR ADULTS WITH ORTHOPEDIC AND/OR VISUAL DISABILITIES

DR. HAROLD WILKE, RETREAT LEADER
FRIDAY, MAY 30, TO SUNDAY, JUNE 1
CAMP CEDAR GLEN, NEAR JULIAN, CA
\$75/PERSON [CAMPERSHIPS AVAILABLE]

LAST DATE TO REGISTER MAY 15
NORM & HELEN STOCKWELL, REGISTRARS
[310] 374-1535
TOM SIMMONS, RETREAT DEAN
[805] 499-6240

DISABILITY AWARENESS SUNDAY MANDATED TO BE OBSERVED IN ALL UM CONFERENCES

In 1996 the General Conference of the United Methodist Church created Disability Awareness Sunday, a new special Sunday to be observed annually by all conferences beginning this year.

Up to now, Disability Awareness Sunday has been a hit-or-miss affair, observed in some conferences and/or local churches, ignored in others.

It was also formerly known as Access Sunday, apparently leaving some people confused as to *who* exactly was being accessed to *what* (or perhaps it was *what* exactly was being accessed to *whom*).

Each annual conference is to set the date of observance and, if it so chooses, direct that a special offering be received to help provide physical and attitudinal accessibility in local churches.*

If your conference has not yet scheduled a Disability Awareness observance, contact your Conference Council of Ministries and request that action be taken to set a date for this

special Sunday. Then contact the Council on Finance and Administration and ask if a special offering is to be taken (and if not, why not).

SEMAR, the Southeastern United Methodist Agency for Rehabilitation, Inc., is mailing out worship materials for 1997 Disability Awareness Sunday which include suggested hymns, prayers, Scripture readings, and sermon-starters. The materials are camera ready and can be used as the worship bulletin of the local church, or SEMAR can send copies available at a printed cost of \$160/1000 copies.

For more information, contact:

Robert M. Pitzer, Director
P.O. Box 128
300 Lakeshore Drive
Lake Junaluska, NC 28745
(704) 452-2881
TDD (704) 452-7640
Toll Free (800) 52-SEMAR
FAX (704) 452-4332

*See the 1996 *Book of Discipline*, pp. 166-167.



CONFERENCE BULLETIN BOARD

VOLUNTEERS WANTED for Habitat for Humanity project to be completed in Redlands during California-Pacific Annual Conference June 8-12. Local churches are asked to provide everything from construction materials to work teams, including disabled workers (believe it or not!), to build the 3-bedroom house. Contact Toni Ethridge, Conference Task Force Coordinator, at 818-767-5197.

A PRAYER AND HEALING Conference will be held July 13-18 at the Oak Glen Christian Conference Center in Yucaipa, Calif. Featured speakers will be Dr. Bob Stamps, Senior Pastor of Clarendon UMC in Arlington, Virginia, and Ellen Stamps, internationally-known author. More than two dozen workshops and several prayer groups are planned. PWDs are welcome and need have no fear of being forcibly healed. Contact Rev. David Walker, Conference Director, at 760-752-1409, or Barbara Roberts, Registrar, at 818-765-9900.

God by nature recruits *outsiders* to be partners in providence, makes a home among them, and through them enriches the *world*. We miss out on this fullness of life when we limit our *partnerships* to those who most resemble ourselves.

—John Koenig—

From *New Testament Hospitality* by John Koenig, copyright © 1985 by Fortress Press.

FROM THE EDITOR: THANK YOU, BISHOPS!



In December of last year, we at *Wings* sent out a copy of the newsletter to each of the 40-some bishops of the United Methodist Church [with the obvious exception of the California-Pacific Conference] with a letter courteously requesting that an address listing of all the churches/congregations in their conferences be forwarded to us. Our aim was, and still is, to raise disability awareness and garner new readers by making *Wings* available to PHUMPS and Friends of PHUMPS nationwide.

Thus far a grand total of four bishops have responded to our request by arranging for us to be sent a copy of their appointments list or addressed mailing labels or, in one case, to be provided with their conference's internet address so that we could download their mailing addresses.

Our thanks to the following bishops for their cooperation:

S. Clifton Ives [West Virginia Conference]

Ann Brookshire Sherer [Missouri East Conference only]

Richard Carl Looney [South Georgia Conference]

Elias G. Galvan [Pacific-Northwest Conference]

We are confident that the other bishops will be equally as forthcoming—eventually.



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

Founder/Editor
Computer Layout/Graphic Design
Jo D'Archangelis

Wings Needs the Following From You
Ideas and suggestions for articles
Original stories, poetry, cartoons
Personal essays and anecdotes
Appropriate items from another source
The name and address of someone who is dying to be on our mailing list
A change-of-address notice if you are moving and want to continue receiving *Wings*

Send All Correspondence To
Jo D'Archangelis, Editor, *Wings*

Church Address
Fallbrook United Methodist Church
1844 Winterhaven Road
Fallbrook, CA 92028
Telephone [760] 728-1472
Fax [760] 728-7433

Home Address
592 West Ammunition Road, Apt. 1
Fallbrook, CA 92028-3191
Telephone/Fax: [760] 723-2668
[Fax Mon.-Sat. 1-4 p.m. Pacific Time]

E-Mail Address
JODARLIS@aol.com



HOW WILL THEY KNOW IF I'M DEAD? A BOOK REVIEW

How Will They Know If I'm Dead?: *Transcending Disability and Terminal Illness* by Robert C. Horn, III, is arguably the most enjoyable book ever written by a person with a terminal illness. Granted this may be a dubious distinction since most books by dying people tend to be sober, and sobering, affairs. Inspiring perhaps, but hardly fun to read.

Horn's book, however, isn't enjoyable merely by default. For one thing, its emphasis isn't on death

and dying, but on life and living. Not exactly what one would expect from a man whose life was invaded in 1988 by amyotrophic lateral sclerosis (ALS), popularly known as Lou Gehrig's Disease.

For another, his book is eminently readable—deftly and straightforwardly written, and laced with humor and high spirits (as well as some nifty cartoons).

Some three years after the initial diagnosis of ALS, this professor of political science at California State University, Northridge, author of academic articles, husband and father of three, and coach of a girls' soccer team, finds himself unable to move (except for his right foot), unable to speak, unable to swallow, and unable

to breathe on his own.

Yes, he admits, it's a bummer all right. But Horn decides not "to get bogged down in thinking about" his mortality. Instead he consciously chooses to get "on with the business of living."

In Horn's case, the business of living consists in voracious reading;

**...What could have been in lesser hands
an eye-glazing exercise in unremit-
ting uplift and pious sentimentality
is, under Horn's foot, a toast to life...**

coaching a fantasy baseball team, *Da Slugs*; and taking trips in a wheelchair lift-equipped van, a portable ventilator his constant companion. He "converses" and writes by pedipulating a computer with the aforementioned right foot. (This living business can be awesomely slow, however—two days at the computer producing about one page of book.)

But while technological support is needed and welcomed, in his eyes it is secondary to the human support he receives from loving family, friends, colleagues, and fellow members of the Northridge United Methodist Church—not one of whom seems to have ever uttered a discouraging word.

Which leads to what may be the main weakness of the book: a lack of

psychological tension and dramatic contrast. Horn deliberately downplays the dark, grungy side of ALS, skipping rapidly, e.g., through the "stages of grief" when he learns of the fatal prognosis.

In life as well as in art, the gloomier the surroundings, the brighter the light seems to shine. Horn's obvious joy in being alive would have had much greater emotional impact if he had allowed us more access to his inner struggles and bouts of depression, feelings which he alludes to but doesn't explore.

With few exceptions, Horn's comments are temperate and tolerant, whether the subject is lousy caregivers or faulty equipment (one notable exception: the justifiably angry sarcasm he aims at Medicare and Blue Shield). He even speaks appreciatively of doctors, thereby verging precariously on the totally unreal.

Nonetheless, what could have been in lesser hands an eye-glazing exercise in unremitting uplift and pious sentimentality is, under Horn's foot, a toast to life, bubbling over with intelligence, charm, genuineness of spirit, and sly wit.

How Will They Know If I'm Dead? probably won't be on Jack Kevorkian's reading list (although Horn does, in principle, support legally assisted suicide). But it should be required reading for everyone who thinks of

(HOW WILL THEY KNOW continued on page 4)



PHUMPS ON-LINE

For the cybernauts (-nuts?) among us, here are a few internet addresses, or URLs, worth checking out.

Mariposa Ministry (a full, rich look at an outstanding Christian-based, peer counseling ministry with disabled young people and adults):

<http://www.satcom.net/mariposa>

Ascension: The Women of Mariposa (true, first-person narratives interspersed with poetry—powerful stuff, but contains depictions of physical, psychological, and sexual abuse of disabled women, so it's not for everyone):

http://www.satcom.net/mariposa/rise_up.htm

General Board of Global Ministries, Health & Welfare, United Methodist Church—Disability Concerns:

<http://www.gb-gm-umc.org/DISC/>

DISC Bulletin Board: Sign up by calling 212-222-2135

Via internet: hwbbs.gb-gm-umc.org

IP address: 198.139.157.121

Disability Awareness Ministries, Inc. (based in the Minnesota Conference of the United Methodist Church, this organization was founded in 1993 to pro-mote church and community accessibility to persons with all kinds of disabilities): <http://www.hamline.edu/personal/gritner/dami.html>

In His Image (also Minnesota-based, this group creates, produces, and presents special programs about disability and the church):

<http://www.hamline.edu/personal/gritner/mimage.html>

Wings Newsletter (yes, we're here!):

<http://www.satcom.net/mariposa/wings01.htm>

LOVE CIRCLES AROUND

By Larry Peacock

Love circles around
Joining hands, linking hearts
Flowing from parent to child
From friend to friend.

Love circles around
Never giving up
Always reaching in.

Love circles around
Pulling down barriers
Building bridges
Kindling hope.

Love circles around
And God's love embraces all.



WORD BITES FROM "HOW WILL THEY KNOW IF I'M DEAD?"

Glasses of Water

It comes down to that old conundrum: do I see the glass as half-full or half-empty?...I am still a vibrant, healthy, and independent person. I can think, reason and analyze, remember, read, write, learn and communicate. I can love, feel happiness and sadness, be enthusiastic, get angry, have highs and lows, feel joy. I can believe, hope and have faith...I am convinced that what I have left is more valuable than what I have lost...All in all, I would say that the glass has lost some of its water but it is still half-full. [pp. 82-85]

To Vent or Not to Vent?

For me, the decision was a slam dunk, a no-brainer, a done deal, a fait accompli...I remember telling Judy, shortly after being admitted to the hospital, that "I don't want to leave here without being able to breathe and eat more easily." That would mean a tracheotomy, with the attached ventilator, and a gastrointestinal tube. If those were what it would take, okay do it! My mind was made up...My guess is that, in my subconscious, I had already decided I wanted to live. Period. [pp. 34-35]

Simply Theological

I believe that God works through people...God's presence in our world is a constant, living, and ongoing one. It is there, obvious to anyone to see or hear, in the manifold expressions of love made by ordinary people (and the scarce extraordinary) every day....Indeed, the gift of love, to love and be loved, is perhaps God's greatest gift. Mine is not a very complicated theology. [pp. 27-29]

Caregivers Anonymous

On a lighter note, we employed for three months a very assertive Egyptian Christian evangelist. To the extreme, it seemed to me...in the middle of a simple procedure he can't do and is overwhelmed by, he would inform me that "Jesus loves you." I always felt like telling him that I know that but, at this particular moment, I wish he could change my shirt. [p. 75]

(*HOW WILL THEY KNOW* continued from page 3)
disability as a prison term and a diagnosis of terminal illness as a death sentence.

As Horn says, paraphrasing a line from one of his favorite movies, *Animal House*: "It ain't over until I say it's over." Now *that's* inspiring!

J. D.

*How Will They Know If I'm Dead?:
Transcending Disability and Terminal
Illness* by Robert C. Horn, III. GR Press/
St. Lucie's Press [Delray Beach, Florida,
1997]. 146 pp. \$12.95 [paperback].

WINGS NEEDS YOUR SUPPORT!

SPONSORSHIPS

Basic PHUMP/Friend Of PHUMPS	\$6-14
Major PHUMP/FOP	\$15-24
Super PHUMP/FOP	\$25-49
Mega PHUMP/FOP	\$50-99
Totally Awesome PHUMP/FOP	\$100 Or More

We need your voluntary financial support if we are to be able to continue publication and make *Wings* available to all PHUMPS. If you think *Wings* is worth it, please make a check or money order payable to "Fallbrook United Methodist Church", mark them "Wings Newsletter", and mail to:

Wings Newsletter
**Fallbrook United Methodist
Church**
1844 Winterhaven Road
Fallbrook, CA 92028

[Donations are tax-deductible to the extent allowed by law.]

Honor Roll Of Appreciation

We thank the following persons or organizations whose gifts of time and/or money have made possible the publication and mailing of *Wings*:

Marie Morse	The Mission Commission
Bob & Betty Jackson	of the Fallbrook United
Roy & Mary Klein	Methodist Church
Ken & Marie Losh	



Fallbrook United Methodist Church
1844 Winterhaven Road
Fallbrook, CA 92028

*"For Disabled United Methodists and
Those Who Care About Them"*

Non-Profit Org.
Bulk Rate
U.S. Postage
PAID
Permit No. 35
Fallbrook, CA

ADDRESS CORRECTION REQUESTED