

Those who wait upon the LORD shall renew their strength, they shall mount up with wings like eagles.... Isaiah 40:31 [nrsv]

Wings

A FAITHLETTER FOR, BY AND ABOUT
UNITED METHODISTS WITH DISABILITIES

Winter 2003 — Vol. 13 Issue 3 No. 51

FROM WHERE I SIT By Jo D'Archangelis

A former Miss America with a hearing impairment receives a cochlear implant and is shunned by the "Deaf Community." A TV news personality with malformed hands intentionally becomes pregnant even though the odds are her child will be born with the same condition and is roundly criticized by a radio talk-show host and his listeners. A young boy born with dwarfism goes through a painful leg-lengthening procedure, a procedure denounced by "Little People" organizations. A longtime wheelchair user declares she would decline healing even if one were offered, and not a few people, disabled and non-disabled, think she's a bit loony.

Two contrasting views of disability are at work here. One is that a disability is the worst thing that could possibly happen to a human being and that anyone who is disabled ought to jump at the chance (so to speak) to be fixed, or restored to "normal" functioning. The other view is that a disability is not something inherently bad but only a "difference" or even (hello!) a "blessing;" either way, it doesn't need to be fixed.

Speaking as a longtime wheelchair user (no, not the one mentioned above), I can say that a disability is *not* the worst thing that could possibly happen to a person (e.g., being married for years to someone you can't stand can be infinitely more horrendous). But the cost of living with some disabilities — physically, psychologically, and financially — can be very high, especially those that prevent participation in most, if not all, of what we consider to be "normal" life activities and that cannot be readily compensated for or those that are accompanied by chronic pain, infection, or life-threatening medical

conditions. Some disabilities are, of course, less costly than others, and some disabilities barely cause inconvenience if they can be readily compensated for.

On the other hand, the disabling aspects of disability are not only in



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the physical reality of the disability itself but also in societal attitudes. Our society often has to be litigiously pounded over the head to provide even the smallest of accommodations for disability. Moreover, living in a society that values perfection of body and...well...*adequacy* of mind over strength of spirit, creativity, and non-conventional beauty, one cannot help but feel the pressure to become more "acceptable" or "normal."

I am neither unacceptable nor abnormal because of my disability, and, no matter how difficult it may be, having a disability doesn't in itself preclude my living a full and meaningful life any more than skin color or ethnic origin does for someone else.

In that sense then, my disability is for me a mere "difference." (A blessing? I don't think so, but I do believe that it has bought many blessings to me.)

Personally, I cannot blame anyone for choosing to fix or alleviate his/her disability if the medical and technological means exist. I see nothing intrinsically wrong with wanting to make one's life easier to cope with. Likewise, I cannot blame anyone for rejecting such means if they feel their lives are perfectly fine just the way they are thank you. Being fixed or cured, while it may enable someone to see or hear better or to walk outside to pick up the morning newspaper or just to look more "normal" (whatever that is) will not make us better people or more human or more children of God. I doubt that it will even make us happier.

If I had the choice, would I be fixed? Ask me during one of my "disability sucks" moments and I'd probably say yes. But even then I'm not what you would call your obsessed-with-cure-at-any-cost type of person. I don't want to undergo anything painful, high risk, or time-consuming. Maybe if someone were to come up with a "fix" in the form of a chocolate bar with almonds...?

Actually, getting up out of my wheelchair and walking is not, and never has been, a big priority with me; what I want and need to do can pretty much be done from a wheelchair. Still, I long to be stronger and more able to do what I want and need to do and, more importantly, rid myself of some pesky medical problems.

Right now my disability choices are very limited and probably will remain so during my lifetime. But if someday I should be presented with a cure or treatment option, I hope I would be able to decide, not on the basis of values imposed on me by non-disabled society or even by a "Wheelchair Community," but on what my mind, my heart, my experience, and the workings of the Holy Spirit lead me to choose as the best way to go for me.

CONFERENCE COUNCIL ON DISABILITY MINISTRY OFFERS ACCESSIBILITY AWARD

Tom Simmons, Chair of the Conference Council on Disability Ministry, has announced the offering of an award for the "Most Accessible Congregation" in the California-Pacific Conference of the United Methodist Church. The award, which includes a \$1000 stipend, will be presented at this year's Annual Conference in June. Applicants will be asked, among other things, to describe their level of physical accessibility, their inclusion of persons with disabilities in leadership roles, and their outreach to persons with disabilities in the community. The Council will be accepting applications through March 30. Applications may be obtained by e-mail, fax, or mail. Contact Jheri Resnik at the Conference office (phone 626-568-7357 or e-mail jresnik@cal-pac.org).

In Remembrance

BOB HORN: WRINGING AS MUCH LIVING OUT OF LIFE AS HE COULD

A widely-respected Professor of Political Science at California State University at Northridge, Robert C. (Bob) Horn III was first diagnosed with Amyotrophic Lateral Sclerosis (ALS), or Lou Gehrig's Disease, in 1988. Eventually he lost the capacity to walk, talk, swallow, and breathe on his own.

During that same time he also continued to be a loving husband to his wife Judy and attentive father to their three children; traveled in a specially equipped van; coached a fantasy baseball team, Da Slugs; wrote articles for his church newsletter; communicated using a computer with his right foot; and published two books, *How Will They Know If I'm Dead? Transcending Disability And Terminal Illness* (1997) and *Whose Right? Who's Right? Seeking Answers And Dignity In The Debate Over The Right To Die* (2001).

I only knew Bob through his books, some newspaper articles about him, and a bit of correspondence mediated through his longtime associate, Gretchen Keeler. He was one of the

most gracious, positive, funny, and — yes — inspirational people I have “never” met. Bob was determined to wring as much living out of life as he possibly could, and that commitment to living was vividly communicated in his words.



This past October, after struggling with a rare form of pneumonia for six weeks at home, Bob was put into the hospital. There he declined further medical treatment thus relieving his family of the anguish of having to make any life and death decisions later on. Keeler reports that “in a last burst of energy” he slowly spelled out with eye movements the words, “I am a lucky man to have such support of family and friends.” He then added, “Don’t get mushy!”

On October 29, 2002, Robert C. Horn III died as he had lived — with dignity and compassion and surrounded by family and friends.

(Hope this wasn't too mushy for you, Bob.)

J. D.

Did You Know It Says Right Here In The Book Of Discipline...?



RIGHTS OF PERSONS WITH DISABILITIES

We recognize and affirm the full humanity and personhood of all individuals with disabilities as full members of the family of God. We also affirm their rightful place in both the Church and society. We affirm the responsibility of the Church and society to be in ministry with children, youth, and adults with mental, physical, developmental, and/or psychological disabilities with particular needs in the areas of mobility, communication, intellectual comprehension, or personal relationships that might make more challenging their participation or that of their families in the life of the Church and the community. We urge the Church and society to recognize and receive the gifts of persons with disabilities to enable them to be full participants in the community of faith. We call the Church and society to be sensitive to, and advocate for, programs of rehabilitation, services, employment, education, appropriate housing, and transportation. We call on the Church and society to protect the civil rights of persons with disabilities.

The Book of Discipline of the United Methodist Church (2000), §162.G

HOPEKEEPERS

A HopeKeepers support/Bible study group for persons living with chronic illness and/or pain is now meeting the third Saturday of every month at the First United Methodist Church, 772 So. Johnson Ave., El Cajon, Calif. 92020. Co-leaders are Joyce Brownlee (619-660-1486, Genwidow@cox.net) and Joann Orendurff (619-449-2082, joannorendurff@sbcglobal.net).

HopeKeepers is a program/ministry developed by Rest Ministries, Inc. Anyone interested in starting a HopeKeepers group may access www.restministries.org/pro-hopekeepers.htm (e-mail rest@restministries.org) for information, set-up support, and resource materials.

CONFERENCE AT CST

The Moore Multicultural Center at the Claremont School of Theology (Claremont, Calif.) is sponsoring a Disability Conference under the leadership of faculty, staff, and students personally and professionally connected with the topic to be held February 24, 25, and 26, 2003, 4:00-6:00 p.m., on the CST campus. Several focus groups will explore ministry issues as they relate to persons with various types of disabilities. Although primarily directed at the CST community, the Conference is open to everyone interested in disability ministry. Contact Dr. Kathy Black at kblack@cst.edu or 909-447-2527 for more information.

It comes down to that old conundrum: do I see the glass as half-full or half-empty?...I am still a vi- person. I can think, reason and ana- lyze, 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."



— Robert C. Horn III, *How Will They Know If I'm Dead? Transcending Disability And Terminal Illness* —



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HEALING FROM THE INSIDE OUT By Lynna Nicholas

Editor's Note: One Sunday morning last October Lynna Nicholas gave a talk at the Memorial United Methodist Church in Oak Ridge, Tennessee. That same day she e-mailed the disability group, Mariposa OnLine, describing her experience after giving the talk. Nicholas has given us permission to reprint both the talk and the e-mail.

THE TALK

Four years ago I came to this church for the first time. Outwardly I looked pretty good; I knew how to smile and look nice. Inwardly I was falling apart.

I have a neuromuscular disease that was diagnosed when I was 12, and I have spent most of my life running and hiding from it. When I came to church, my disease had progressed to the point where I couldn't hide it anymore. I recognized that I needed something because I wasn't holding it together anymore. That something was God.

It just blew me away that even though I had run from God for 20 years and had sinned badly, so badly that I thought I could never be in his presence again, he said to me, "No, my love is bigger than the bad things you have done." God welcomed me home. I can't tell you what that has done in my life.

At the same time that I had this awesome experience of being unconditionally loved, I started experiencing pain and anger. I didn't know where these negative feelings were coming from. I now recognize that they were part of a healing process. I have this image of God sitting in a bulldozer plowing through the walls that I had built around myself. Then he steps off the bulldozer onto an excavator and starts digging into my memories and pain, all the places that I didn't want anybody to know about, including myself.

As I struggled with God over my disability, I realized that the deepest point of pain in my life was thinking that I was "damaged goods" and that my Creator had made something that was garbage.

Once I finally stopped struggling with God and raging at him (and believe me, he allowed me to rage), at that point where I said, "OK, I accept this and I am going to love you no matter what," God started showing me in awesome ways that I was *not* garbage. I can get up here before you today and tell you that our God is still in the miracle business. Even though my legs aren't healed, God has changed me from the inside. Even though my disability has progressed to the point where I need to use a wheelchair sometimes, I can say that I am fearfully and

wonderfully made.

I have never felt so whole in all my life now that Jesus Christ is in it. I used to be a fearful, scared, angry person, but now Jesus is creating peace, joy, and hope within me. His graces just keep coming and coming. He has given me this opportunity to serve him by telling you what an awesome thing he has done.

That's why we are here as the Church. When we talk about signing up for ministry and service, it is because our God is out there searching for people to show that they are not garbage, to show that they are precious beloved treasures...his children. God has chosen us to give voice to that way of seeing people and to go into the world to participate with him in redeeming it.

AFTER THE TALK

Today, I stood up in front of my church at two different services and talked in public for the first, and

second, time in twenty years. I used to get sick at my stomach in college speaking on subjects like ion chromatography or the effects of potential inhibitors of acetyl cholinesterase. (Don't worry if you don't have a clue about what I just wrote — I don't either!)

Today, however, talking about how I have felt all my life as a person with a disability and the way God is healing me from the inside out was sublime. I was scared, to be sure, but I have never felt like something was more right in all my life....

A young woman came up to me afterwards and waited until all the other people had had their say. My words seemed to have touched a nerve with quite a few folks, but she stood out. She said to me, "You don't know me. I am just visiting your church, and I wanted you to know that I too am damaged and Jesus is healing me and beginning to use me too." I asked her how she was damaged, more than a little puzzled because she was so young, fresh-faced, and seemingly healthy. She told me that she had been the victim of sexual abuse. She then said that she had found healing in my words.

Today I didn't hate my disability.

Today I was used as a healer.

Today I thanked God for the joy of being me.

Can't wait for tomorrow.

LIFE IS A GIFT

Dear Lord life is a gift a dance a chance
 Glorious and grand fearless and sad
 So running
 Downhill
 Breathless
 Out of control fast
 Scared to look now in the eyes
 Crying then laughing at how serious I am
 The joy that bubbles out
 Uncontrolled
 In the supermarket
 Or...holding...a...yoga...pose...for...four...minutes
 The try your best don't be late dear attitude
 From my mother passing on to
 My daughter and yes
 I've heard her use the same words with her son
 In short I want to thank you
 For the joy in this life
 That picks me up when I fall
 That whistle a happy tune fly me to the moon type
 I wouldn't have missed this ride for anything

— Norma Lee Macia —
 July 2002

Macia has lived with multiple sclerosis for 20 years. This poem is dedicated to the MS Support Group of Orange County [Calif.].



MENTAL HEALTH MINISTRIES HELP CREATE CARING CONGREGATIONS

Through the new Mental Health Ministries created last summer by the California-Pacific Conference of the United Methodist Church, new coordinator Rev. Susan Gregg-Schroeder is working to help local churches become aware and involved at some level in outreach to individuals with mental illness and their families.

Rev. Gregg-Schroeder says mental illness can affect persons of any age, race, religion, or income. Mental illnesses are not the result of personal weakness, lack of character, or poor upbringing. More than 7 million people in this country and over 5 million children and adolescents suffer from a serious chronic brain disorder. The stigma of mental illness isolates and marginalizes people, keeping them from seeking appropriate medical, therapeutic, and spiritual help, she

said.

“Mental illness awareness is a justice issue,” said Rev. Gregg-Schroeder. “As United Methodists, we are all to get involved in the systemic problems that affect persons with mental illness. Many persons with mental illness are among the poorest of the poor in physical needs and psychological needs. At least one-third of the homeless and one-third of our prison population suffer with chronic mental illness. Many persons with mental illness lack adequate housing, lack job opportunities, or lack basic needs such as essential health-care and supportive services.”

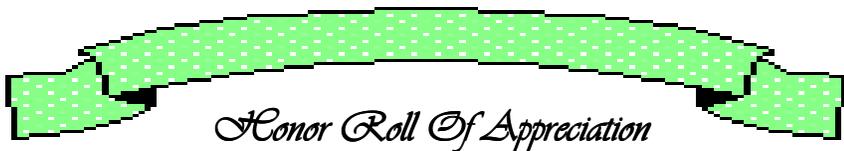
Our churches can be a source of hope, support, and healing, the conference coordinator reminds. Persons with mental illness and their families will often come to a clergyperson first, but many of our ministers and church

leaders are not equipped to address their needs. Resources are available through a variety of sources like the local chapter of the National Alliance for the Mentally Ill (NAMI).

Mental Health Ministries has produced a 25-minute video titled “Creating Caring Congregations” that lifts up the stories of an adolescent, an adult, and an older adult as well as the five-step “Caring Communities” program developed by the General Board of Church and Society to help local churches (see the GBCS website www.umc-gbcs.org/heare-2.htm for worship resources).

Rev. Gregg-Schroeder is available to come to local churches to do workshops on various topics of mental health (sgschroed@cox.net). She served for 13 years as associate pastor at First United Methodist Church in San Diego and is a member of the American Association of Religious Counselors.

Excerpted from *Circuit West*, the newspaper of the California-Pacific Conference of the United Methodist Church (Sept. 13, 2002)



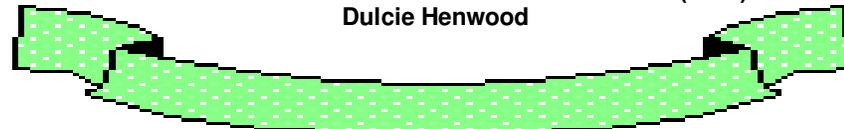
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I Am Disabled And...

It was you, LORD,
who formed my inmost parts;
you knit me together
in my mother's womb.
I praise you,
for I am fearfully
and wonderfully made.
Your works are wonderful;
I know that very well.

Affirmation #3 adapted from
Psalm 139:13-14 (NRSV) by
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