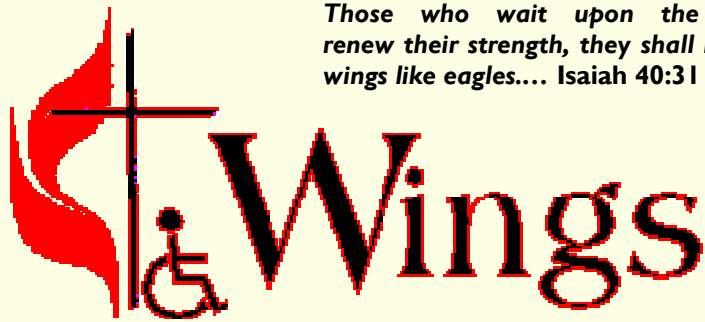


*Those who wait upon the LORD shall renew their strength, they shall mount up with wings like eagles.... Isaiah 40:31 (NRSV)*



**A FAITHLETTER FOR UNITED METHODISTS WITH  
DISABILITIES AND THOSE WHO CARE ABOUT THEM**  
Summer 2005 — Vol. 16 Issue 1 No. 61



## **FROM WHERE I SIT: OF TURNIPS AND HUMAN BEINGS** By Jo D'Archangelis

If there was anything clear about the Terri Schiavo story as it unremittingly played out on the media, it was that there wasn't a whole lot very clear about it. At least not to my mind. Of course, in the minds of those

**I myself would not have wanted to live in Terri Schiavo's condition—that is, used as an unwitting pawn to further the religio-moral-political agendas of various groups.**

strongly supporting one side or the other, the facts were self-evident and the conclusions to be drawn incontrovertible.

What is known for certain is that in 1990 a young woman named Terri Schiavo stopped breathing for five minutes and suffered brain damage that left her unable to walk, talk, or swallow. She was housed in institutions for the next several years where she received 24-hour care and took nourishment through a feeding tube (considered to be an "extraordinary medical measure").

In 1998 her husband and legal guardian, Michael Schiavo, petitioned the court, in the absence of any written directives on Terri Schiavo's part, to have her feeding tube removed—in effect, dooming her to die. Her parents, Bob and Mary Schindler,

fought against the petition in Florida and federal circuit courts insisting that with the proper treatment their daughter would recover. From 2002 to 2004 they were successful in having the tube repeatedly reinserted after it had been removed. Eventually, the Florida legislature, the Florida governor, and even members of the U. S. Congress were to be caught up in the fray.

In early 2005 the U. S. Supreme Court declined to hear the case. In March of that year Michael Schiavo's petition was upheld by the Florida circuit appellate court, and Terri Schiavo's feeding tube was removed for the last time. She died of dehydration nearly two weeks later. A subsequent autopsy revealed that she had indeed been suffering from major brain damage and that she was blind.

Was Terri Schiavo, as most medical authorities and her husband believed, in a "persistent vegetative state" without cognitive or emotive capacity, unable to experience either pleasure or pain or to

respond in any meaningful way to external or internal stimuli? Would she have preferred to be dead than to, as her husband put it, "live in this condition"?

Or was she, as her parents and many Christian right-to-lifers and some disability advocates believed, a severely disabled person who nonetheless was able to respond, albeit in minimal fashion, to her environment? Did she have an inherent right to be kept alive?

Now that the Terri Schiavo story is behind us to some extent, I have come to my own not necessarily incontrovertible conclusions regarding this whole very tragic affair:

1. Everyone should put in writing, in a Living Will or whatever, what they want to happen to them—or not happen to them—if they should wind up in Terri Schiavo's condition and thus avoid becoming the number one news-story for weeks on end on CNN and Fox News.

2. Doctors don't know everything, especially when it comes to how much consciousness of their outer or inner world,, including the capacity to experience pain or pleasure, may be had by human beings who appear to be non-functional on any observable physical level. As an example in a related area: the common wisdom among medical experts for years was that newborns cannot feel pain and therefore specific measures to avoid or relieve pain in postnatal procedures need not be taken. This policy was changed a few years ago, but whether on the basis of new scientific information or on the general moral principle that when in doubt

*(FWIS continued on page 2)*

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err on the side of not causing pain, I don't know.

3. Starvation is not a humane and acceptable method of euthanasia in a supposedly civilized society.

4. Feeding tubes should not be considered as "extraordinary measures" in the same category as antibiotics and kidney transplants. Feeding tubes enable human beings who would otherwise be unable to do so to take in nourishment, a basic function necessary to human life. This applies to respirators as well, since breathing is, unless I'm mistaken, a basic function necessary to human life.

5. I myself would not have wanted to live in Terri Schiavo's condition—that is, trapped for years in a nursing home; caught between loved ones in a bitterly fought legal battle as to who really had my best interests at heart; and used as an unwitting pawn to further the religious-moral-political agendas of various groups and media attention grabbers.

6. Many people—dare I say even good, decent, Christian people?—have chosen and continue to choose to have loved ones in Terry Schiavo's condition euthanized. Some of their reasons may be base (a desire to rid oneself of a financial, physical, or psychological burden) or noble (to sincerely do what they feel their loved one would want them to do or to simply end what they perceive to be their loved one's suffering). But for the most part their choice reflects their own natural feelings of helplessness and hopelessness and their need to relieve their own suffering in the face of something incomprehensible and intolerable. Whether base, noble, or natural, such reasons do not justify taking another person's life, especially when that person cannot speak for him- or herself. Furthermore, death permanently forecloses the possibility of new information or medical technologies or second thoughts. Nothing can be reversed, rectified, or redeemed. Therefore...

7. Family members, next of kin, and/or legal guardians should not be given the legal right or, more accurately in some cases, the legal burden of determining if someone who is non-terminally ill but in a "persistent vegetative state" should be allowed to live or die. Finally...

8. The term "persistent vegetative state" should be deleted from the medical lexicon. No matter what their state or how persistent it may be, human beings are not turnips.



## "Where There Is No Vision, The People Perish" (Prov. 29:18)

### Interfaith Disability Pre-Summit

Tuesday, September 21,  
2005

Meeting: 2-5 p.m.

Dinner: 5-9 p.m.

St. Elizabeth's Episcopal  
Church Parish Hall  
1830 Connecticut Ave.  
Washington DC.

The Pre-Summit will be held prior to the Many Voices/One Vision Disability Summit, a conference of secular organizations working in the area of developmental disabilities meeting on Thursday, September 22 and Friday, September 23, 2005, at the Washington Hilton in Washington DC.

This is a unique opportunity for faith-based organizations to participate in a national event where secular organizations will meet, to explore issues of common concern in the area of developmental disabilities, and to add a faith-based perspective to discussions of these issues on both a national and state level.

If you would like information about registration for and/or sponsorship of the Interfaith Disability Pre-Summit, contact Sr. Gabrielle Kowalski, President, AAMR Religion and Spirituality Division, at 414-410-4109 or gkowalski@stritch.edu.



A non-official, non-profit quarterly newsletter published for, by, and about United Methodist adults with disabling conditions

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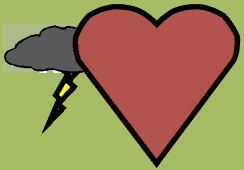
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## KEEPING THE FAITH: AN INTENSE RELATIONSHIP WITH GOD

By Josie Byzek

Lutheran pastor and rehab chaplain Bernie Jorn dove into a lake when he was 17 and emerged a quadriplegic, which threw his self-identity and his faith into a centrifuge. Gone was the young swim team captain and saxophone player and in his place was a man who stormed at God.

"The intense suffering led to an intense relationship with God that would not have been there," he says. And that relationship was anything but smooth at the beginning. "Husbands and wives will yell at each other when they've been hurt, but that's because they know that person's not going to leave them," says the Jacksonville, Fla., minister. "In yelling at God, I guess I built up a relationship through anger. Everyone kept telling me how great it was that God loved me. Well, I didn't feel that much love."

Once his storm of anger passed, though, Jorn began to experience God as a greater expansion than what he ever thought or felt God could be. "It's something that I can't put into words, and therefore is deeper than anything I can understand. It's like falling in love. How do you explain falling in love?"

Eventually Jorn's new relationship with God led him to become chaplain of the Brooks Rehabilitation Hospital and interim pastor of Faith Lutheran. Jorn calls doing pastoral care from a wheelchair a "double-edged sword." On the one hand, some people relate to his disability, which gives him credibility, "but sometimes people don't feel permission to express their own anxiety, their own pain." Someone with a busted knee might see Jorn and think he has nothing to complain about. "And it was hard for me to get past that too, you know? I was like, 'Hey, you got a busted knee, what do you have to complain about?'"

But then Jorn sits with the person, and sees beyond the physical condition into

the person's emotional state, something he can eventually do because he works at developing his relationship with God. "Christian theology is one that looks at the world as being a world of pain and suffering—and alleviating it as much as

**Once his storm of anger passed, though, Jorn began to experience God as a greater expansion than what he ever thought or felt God could be.**

possible through a relationship with Christ," he says.

Yet the discomfort many churchgoers feel toward wheelchair users—and wheelchair-using pastors for that matter—is really just a sign of the world we live in, says Jorn: "We're used to people in wheelchairs who are in hospitals or who are sick or elderly, but not who are

in an authority position or in a leadership position." He says it's interesting to see how people react to him at the end of a service. "People are used to coming up and shaking the pastor's hand. I tell them to put a hand on my shoulder, grab my wrist, it's always good to give me a hug. It's a different way of saying "hello" at the end of the service, and that takes some education. After a while they start to see me more than my disability, but it takes time."...

It's people of the cloth like...wheelchair-using pastors who, by simply being faithful to their callings, are leading the

Christian church to a new understanding of what the disability experience can mean. Through their struggles and leadership a new church is being born, one in which—someday—wheelchair users will regularly be seen as leaders as well as members.

Excerpted with permission from *New Mobility* (Dec. 2002)

## WITHOUT THIS FAITH

By Helen Keller

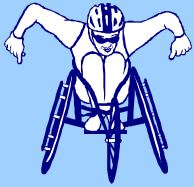
Without this faith  
there would be little meaning in my life.  
I should be  
"a mere pillar of darkness in the dark."

Observers in the full enjoyment  
of their bodily senses pity me,  
but it is because they do not see  
the golden chamber in my life  
where I dwell delighted;  
for, dark as my path may seem to them,  
I carry a magic light in my heart.

Faith, the spiritual strong searchlight,  
illuminates the way,  
and although sinister doubts lurk in the shadow,  
I walk unafraid towards the Enchanted Wood  
where the foliage is always green,  
where joy abides,  
where nightingales nest and sing,  
and where life and death are one  
in the presence of the Lord.

(Editor's Note: We found this poem attributed to Keller in another newsletter but without any further source information.)





## TEEN OVERCOMES OBSTACLES TO WIN IN PARALYMPICS— AND LIFE By Melissa Lauber

**W**hen Tatyana McFadden, of Linden United Methodist Church in Clarksville, Md., was 3 years old, she learned to walk— upside down, on her hands. Today, McFadden is one of the fastest racers in the world.

In September [of last year], instead of starting her freshman year of high school,

she raced in four events at the 2004 Paralympic Games in Athens, Greece. She won a silver medal in the 100-meter and a bronze medal in the 200-meter wheelchair races. The games followed the summer Olympics in Athens.

The excitement of her victories rolls on. When she returned, McFadden was a guest of the Smithsonian Institute's new exhibit, "Breaking Records, Breaking Barriers," met President George W. Bush, and is teaching disabled soldiers returning from Iraq how to race.

Her journey to become a Paralympian

has been a remarkable one, said her mother, Debbie McFadden. When Tatyana was born in St. Petersburg, Russia, her caretakers at the orphanage where she lived prayed that she would die. Her spinal column was exposed, her mother

**Tatyana knows God is with her, and her spirituality is reflected in her style of racing. "I love competition," she said. "I love going fast."**

recalled. "They couldn't understand why God kept her alive. It puzzled them, and they wondered what kind of life this child could possibly have," she said....

When Tatyana was 6, McFadden encountered her during a fact-finding mission while working as the presidentially appointed U.S. commissioner on disabilities. Touring Russia, McFadden walked into a room at the orphanage. Tatyana immediately claimed her as her mother....

[McFadden] admits she is not certain of the exact reason God saved Tatyana.

"Maybe it was to be a world-class athlete. But I know God has plans for her."

In addition to a family, a wheelchair, and the opportunity to pursue a dream, McFadden also gave her faith to her daughter. Tatyana knows God is with her, and her spirituality is reflected in her style of racing. "I love competition," she said. "I love going fast." She is energized by the crowds, like the 24,000 people who cheered her at the qualifying race in Sacramento, Calif.

But rather than defeating opponents,

Tatyana focuses on doing her best. "Each time, you try to beat your personal best. that's the goal," she said. To ac-

complish this, she trains for an hour a day and often cross-trains, playing basketball [and] ice hockey and swimming. Nothing seems to daunt her. She even goes up escalators at the mall in her wheelchair, her mother reports.

McFadden is glad that her daughter is willing to strive. "Life is full of challenges," she said. "You never give up. In our darkest hours, we don't always see the light." As a parent, her job has been pointing Tatyana toward the light.

Tatyana thanks her church and its pastor, the Rev. David Carter Rimbach, and his wife, the Rev. Joan Carter Rimbach,, for making the building accessible—even carrying her places where her wheelchair could not go.

The McFaddens are concerned that some churches still are not accessible for people with disabilities. When Tatyana was adopted, she came to a land that had religious freedom, Debbie McFadden said. "Yet that same religious freedom is denied to some people by some churches." Accessibility is essential, she said. "But the biggest barrier is attitudinal."

Having the right attitude is essential to racing and to life, Tatyana said. For those who would pursue their dreams, the young Paralympian offers simple advice: "Just do it. If you want to do something well, practice makes perfect."

Abridged from a UMNS release, Oct. 20, 2004. Lauber is associate editor of the *UMConnection* in the Baltimore-Washington Conference.

## HELEN By Beth Porter

I live in a L'Arche community, a community for people with developmental disabilities and those who share life with them. Once a week, early in the morning, I help Helen prepare for her day. Invariably Helen, a petite, rotund little woman, is sitting up, wrapped in her comforter, smiling benevolently as I enter. Her peacefulness fills the room. In a way, Helen sanctifies the room with her smile and welcoming presence, making it a space where the experience of God becomes available to those who come to help her. I look forward to the quiet few minutes we will share together in her room, and I live the rest of my day more centered and attentive to God and God's people. Helen does not talk, but she doesn't need to talk to be a blessing and to bless her surroundings. A rabbi friend of our community once commented in a public gathering that if people are created in God's image, then in some way God must resemble a person with a developmental disability. "Think about that!" he urged his listeners. I do....

Excerpted from "Making Enough Room For Joy," *Alive Now* (May/June 2001). Porter serves on the pastoral team at L'Arche Daybreak, near Toronto, Ontario. She writes on spirituality and interfaith matters.



## ON COMING HOME TO MYSELF

By Rev. Mitzi N. Eilts

I'm almost 50 years old and have been female my whole life. For most of my adult life I've been at home (spiritually and emotionally) with the facts that my identity is not heterosexual and my life partner is another female. For all the rejection, oppression, and hatred that truth can evoke—coming home to myself has been a gift of God's good companionship.

Are you wondering what all this has to do with disability? Coming to experience my whole identity as holy gift, including my particular embodiment as female, has been great preparation for coming home to myself as one with a chronic disability.

I have remitting-relapsing multiple sclerosis (MS), diagnosed four years ago. While I may escape significant deterioration of physical mobility, I meet chronic fatigue, sight issues, overt problems with heat and stress, and difficulties with hand coordination and cognitive dysfunction.

Neither my disability nor my sexual orientation is immediately obvious. Only when I make them known are others aware.

MS, like my sexual identity, has caused me to look into who I am, the meaning of my life, and where and how God moves in all that. I have gained new, different connections with the Divine, myself, and others.

Changed, not devastated, I made serious internal adjustments in self-view and self-expectations. I learned about MS, what the medical world doesn't yet know about it, and treatment options. Flexible health insurance gives medical choices and resources, an important factor in my ability to cope.

From the beginning I refused to let any sense of shame, others' or my own, make me hide what I live with. Informing people about my MS could negatively affect their view of me and limit their expectations.

So why do I share this information? In coming "out" of the closet years ago, I learned that hiding parts of myself is dangerous and destructive to...my physical and spiritual and emotional self.

My soul is healthier in my body and spirit when I avoid expanding energy hiding who I am and how I'm feeling. My

**For me, the lesson is obvious and universal. The more diverse those who are included in being the church are, the more welcoming a church can be.**

disability is somewhat invisible; as long as I don't tell, it is assumed I am able-bodied.

So I tell—neither for sympathy nor excuse but to be associated with anyone whose differences cannot (and should not) be hidden. I became one more "demanding" person seeking justice (accommodation and change) and a full place in society with all my imperfections and talents.

I have become sensitive to making the church (and all society) hospitable for all. I noted at the coalition's\* national gathering how much all have to learn about making the church a place where everyone can come and be welcome.

From the first meeting, planners kept in mind hilly Seattle campuses. We reduced transitions between buildings. We

\*Eilts is national coordinator for the United Church of Christ Coalition for Lesbian, Gay, Bisexual, and Transgender Concerns.

budgeted for vans, ASL interpreters, and childcare. We assigned persons to contact registrants indicating specific needs.

It wasn't enough. We could have had a greeter out front to assist with problems. Lift-less vans were useless for wheelchair-users who cannot step up....

We must utilize the expertise of those trained to look at all possibilities and know the pitfalls of sincere but inexperienced solutions. That's true whether talking about differences in abilities, race and ethnicity, class, gender and sexual identity, or language.

For me, the lesson is obvious and universal. The more diverse those who are included in being the church are, the more welcoming a church can be.

With MS, I have found, once again, what it means to believe as I say I do. Loving God with my body, soul, and mind is essential to being spiritual. Loving my neighbor as myself is to be faithful.

Working with my body and mind—in thought and spirit, connecting with others, with creation, with silence, with ideas—is where and how I encounter communion with God.

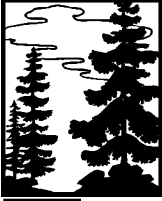
Persons with disabilities know in body and soul the struggle to love ourselves and to love God with our whole selves. We meet these realities daily, moment by moment. Although no one has all the answers, each has unique insights to bring to the mix of this reality that points to Truth.

**From *That All May Worship and Serve*, the newsletter of the United Church of Christ Disabilities Ministries and Mental Illness Network (Jan./Feb. 2003)**

### *I Am Disabled And...*

Just as each of us has one body with many members, and these members do not all function the same, so in Christ, we who are many form one body; each member belongs to all the others, and we each have different gifts, according to the grace given to us. I thank you, LORD, that the Body of Christ is not complete without me.

**Affirmation #13 based upon Romans 12:4-6 (NRSV) by Ken Tittle and Mariposa Ministry and Mariposa Online.**



## CAMPERSTAKE STOCK OF SPIRITUAL GIFTS AT DISABILITY RETREAT By Bruce Baraw

Twenty-seven people coming from Santa Barbara to the Imperial Valley in Southern California gathered at Camp Cedar Glen in Julian, Calif., June 3rd through 5th for the 14th annual Earl Miller Memorial Spiritual Life Retreat. The Earl Miller retreat is for persons with disabilities, their caregivers, and family members.

Recent Claremont School of Theology graduate and founding member of Mariposa Ministry, Lupita Alonso-Redondo, led the group in worship and prayer and guided them in taking stock of their Spirit-given gifts to bring in ministry to others. Retreat dean Dee Baraw and music leaders Paul Cogger and Santiago Redondo joined to provide music, movies, games and crafts in a diversity of activities and experiences.

Thanks to camp manager Cory Jones and his staff, all campers in attendance enjoyed the beautiful, peaceful and well-fed comfort of Camp Cedar Glen.

The Earl Miller Retreat is sponsored by the California-Pacific Conference

Committee On Disability Concerns and the Board of Camping, Outdoor, and Retreat Ministries. The 2006 retreat will be held at Camp Cedar Glen June 9-11. For more information, contact Dee Baraw at 619-337-0746 or SDUM-CampsDee@aol.com.

Baraw is a member of the Committee On Disability Concerns of the California-Pacific Conference of the United Methodist Church.

### *Honor Roll Of Appreciation*

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