

The Stem Cells Road to Ruin (introduction)

A Diary of Mankind in Despair

A common ground we can *live with*:

Faced with the following, which would you choose?

- You're diagnosed with a degenerative disease, or you suffer a catastrophic injury. You face permanent disability followed by lingering death. Your doctor reports that your condition is incurable. Science, he explains, is working on it. Maybe a treatment will reach you in time, but probably not. You're told to accept your changed life - to make the best of it.

Or...

- Faced with the above, your doctor assures you with a smile that your condition *can* be managed or cured - that you'll soon be living the life you *want* to live, as good as new.

Choose well. You stand a one in eleven chance of facing *the first* of the above fates - every year. Choose well, because you *do* have the power to choose.

A *stem cells and cloning* war is being waged in Congress. It's being waged at the United Nations, in newspapers, in political elections, at universities, in government and religious institutions. The lives of over one hundred million Americans may be profoundly affected by its outcome. The future of global healthcare *will* be affected. This war concerns the priorities and directions of basic medical science. It concerns pharmaceutical and biotech industry financial goals.

At its root, the stem cells war is about you and your life.

For the first time in history and probably the last, you have a voice in the direction of science. You can stand up and be counted regarding the goals and priorities of publicly funded research. Resources can be used efficiently to save human lives and improve human health, or used to protect basic research growth and pharmaceutical profits. It is *because* of the stem cells and

cloning moral debate that you have a unique opportunity to be heard, to influence your possible medical future. But you won't have it for long.

This window of opportunity is closing. As long as a *moral* debate rages over embryonic stem cell use and human cloning, the issue of therapeutic *practicality* concerning bio-medical research will be newsworthy. Politicians will continue to consider your views regarding the direction of science, its priorities and goals. But the more society accepts overblown hype regarding industry preferred research agendas, the more practicality becomes politically moot.

Regardless of conflicting political, religious, or worldviews, we *all* want to live, to be healthy. We *all* want our loved ones to be happy and whole.

“The Stem Cells War” reveals:

- The scientific and medical facts of these issues in common sense layman's terms.
- Why the *words* of national leaders on *both* sides of these debates proclaim one thing, but their *actions* promote something else.
- How research studies can be *designed* to fail, misleading the public for the financial gain of industry and science.
- The colossal dollars at stake, financial ties, and personal ambitions that entice those we trust to betray it.
- That the best within us – our compassion for others, our longing to live, our social and moral passions – are being exploited by experts who know how to pull our strings.

“The Stem Cells War” offers a common ground we can live with - a platform of sense regarding science, a platform that lays bare the ties between *its* direction, *our* future, and the choices before us.

“The Stem Cells War” allows you to choose well regarding which stem cell path best promotes the future you want if you're faced with a medical crisis - to hopelessly suffer, or to live a life of your choosing.

Foreword

I used to look away from people in wheelchairs. Now I live in one.

It wasn't that I didn't care. Disability scared me stiff, so I refused to look at it. Now I don't have a choice. The point?

Before becoming paralyzed when I considered science at all, or the ethics of science (bioethics), I reassured myself that these were not *my* concerns. They belonged to someone else. Now, with my life and dreams at the mercy of science, I've discovered just how *much* I care about disability and disease, just how much the concerns of science are *my* concerns.

Yet, when I was healthy and hiking mountains, I never thought that I'd end up like this - unable to walk, my body unable to feel, my future dependant on science.

For four years I've been active in the nation's 'stem cells and cloning' debate as a *pro-cures* advocate. Through firsthand exposure to politicians, reporters, scientists, and actors I've learned that *everyone* in these issues has an agenda - personal, industry, or organizational ambitions that stand to be sharply affected by the outcome of these debates. I have one too.

I have a personal bias where science is concerned. I don't belong to political party. I don't take sides on abortion. I don't belong to a religion. I don't own research patents or biotech stock. I want to walk again. I need *more* than hope from publicly funded science. I need a cure.

A physical way of life

When young and single I dabbled in karate, modern ballet, hatha yoga, and running. In 1984 I married Selene, an avid hiker who I'd met while teaching yoga. We refurbished old houses, refinished and upholstered furniture, and covered antique lampshades for fun. Our passion was hiking - first Pennsylvania's Appalachian Trail while I worked for Conrail, then the Colorado Rockies while in Denver with the Southern Pacific.

For us, Colorado was eighteen months of heaven.

In May of '97' my job moved to Omaha when the Union Pacific bought the SP. Since Nebraska has no mountains to hike, I took a position with Montana Rail Link, a regional railroad in Montana's Bitterroot Mountains.

On June 20th while returning to Colorado to bring Selene to our new home, I grew sleepy while driving. I pulled into a truck stop for coffee. Instead I bought an artificial cappuccino that didn't have a caffeine kick. I bought what *looked* enticing, what caught my attention - not what I *needed* to stay awake.

I drove onto the Interstate. Within ten minutes I fell asleep, drove over a hill, ruptured a disk, and bruised my spinal cord.

I awoke with my family all around, but without a clue of what had happened or where I was. Selene *should* have been in Colorado with our dog and cat, but she was with me. My father and sister *should* have been in Pennsylvania, but they were here too. I felt so utterly weak and barely 'there' that I had to be *barely* alive. Something had happened, something terribly wrong.

The first few weeks passed in a jumbled nightmare of survival, recall, denial, and desperate hope. An orthopedic surgeon prodded my feet daily for signs of returning life. His parting smile

grew more brittle and forced with each passing day, giving the lie to meaningless winks and nods.

The blackest day in my life was the day that someone parked a wheelchair outside my door, but visible from within. I kept hoping that whoever owned it would return and claim it. But it just sat there, waiting. It was like the chair was staking a claim on the rest of my life. Today, nine years later, the thing in my chest that I call 'me' still *crawls* when I think of it.

At first I was paralyzed from the neck down, blind in one eye, and mostly deaf. When the spinal shock wore off I regained the use of my hands and arms. My sight and hearing eventually returned. But I remained impotent, without functioning bladder or bowels, without sensation over most of my body, without voluntary movement below the shoulders.

Actor Christopher Reeve once told the U.S. Senate, "Now some people are able to accept living with a severe disability. I am not one of them."

I couldn't agree more.

I have a bad attitude about being paralyzed. I was told in rehab that my life was *not* devastated. It was merely 'changed.' I didn't agree then, and I still don't. By my standards, when I lost the ability to walk, to run, to dance, or stand – to feel the wind, the sun, the rain, or a soft caress – to eliminate bodily wastes, or make love – my life wasn't *changed*. It was trashed.

When after months of rehab I was told by my doctor that I'd never walk again, that my "one chance in a hundred" had fizzled, I bravely retorted:

"You don't understand! Not only will I walk again, but I'm going to climb Lolo Peak! (a nice hike in Western Montana)

Nine years later I'm still sitting. I share these things to explain my agenda.

I want out of this wheelchair. I want my life back. I want my wife to *be* a wife and *nothing* but a wife, not my caregiver. I want others in my position, or those with Heart Disease, Diabetes, Cancer, Stroke, Alzheimer's, Parkinson's, etc., to *also* regain the lives that *they* want, not the 'changed' lives they're told to accept. I don't want anyone to suffer as I've suffered, or as my wife has suffered, not if it can *possibly* be avoided.

After looking away from disability before my injury, then living the horror of it, I can say with certainty that, for me, living with disability is no better inside looking out, than outside looking away. Others have learned to cope with disability or disease, to forge ahead, building new lives in new directions. I respect and admire those who can and those who've tried, but can't. But some part of me will always be a hiker climbing mountains with his wife.

It's the best within me holding on, refusing to surrender its dreams and accept that a broken spinal cord can't be mended.

“The Stem Cells Road to Ruin” presents the journey I’ve taken to recover my dreams, on a road with wholly unexpected and sometimes ugly turns – a road I share with all mankind. It can lead to where we want to go, or where others want to take us.

Where the road goes and how quickly it gets there can be your decision, or you can “look away” and let others decide.

Intro and Foreword: 1,723 words 8 pages double-spaced (intro 3, foreword 5)