

you been scouts' or better yet . . . "are any of you eagle scouts?"

Turning to the impact of scouting on my personal life, first and foremost scouting afforded extraordinary opportunities to build lasting and remarkable bonds between my father and myself and my son and myself. My son is an eagle scout, and we continued into adulthood many of the pursuits we first enjoyed together in scouting. The last adventure we undertook before he died this past year found us standing together on the north pole, much as we had stood together on mountain peaks in Colorado during his youth. Many of my fondest memories of Greg were inspired by our experiences in scouting.

That is not to say that those experiences were invariably easy. I have been to both the north pole and the south pole, but by far the coldest I have ever been was on a cub scout picnic! And there was the time when I was the only adult available to take my son's patrol on a long-anticipated hike. There was one minor problem: My leg was in a cast and I was relegated to walking with crutches. I assembled the boys and told them, very forcefully I thought, that I would serve as their adult leader . . . but only on the condition that they never get so far ahead of me on the trail that they could not see me: Whenever I should begin to drop out of sight they were to stop immediately and wait for me to catch up. All expressed enthusiastic agreement with this policy . . . so the hike began.

That was the last time I laid eyes on any of the boys until I came across the campsite they had established for the night!

Scouting of course helps prepare one for the challenges of life. In that regard I recall fondly the time my son and I became lost while backpacking in the Rockies. I immediately began sighting nearby mountain tops with my trusty compass. Greg, being of another generation, smugly whipped out from his pack a hand-held GPS receiver. After a few minutes of button-pushing and several puzzled glances at our map, he announced, "I know exactly where we are, dad. We're on that mountain right over there!"

This sort of thing may be the reason why my loyal wife, mother of an Eagle Scout, wife of an Eagle Scout, has over the years gradually come to consider "roughing it" to mean a slow bell hop!

Those not familiar with scouts and scouting might ask, do you really enjoy sleeping in the rain with a rock poking you in the ribs after a dinner of burned hot dogs and sandy marshmallows? Truthfully, the answer is no.

So then why do we do it?

I found the answer to this question when I was serving as Under Secretary of the Army and was visiting the 82nd Airborne Division. Talking with a grizzled old paratrooper who had parachuted more than 1,000 times, someone remarked that he certainly must like to jump. To our utter surprise, he responded, "I hate it". Asked why, then, in a volunteer Army, did he do it, his answer was simple: "I like to be around the kind of people who do."

There is in fact a certain kinship among all who have ever been involved in scouting. For example, there was the occasion a couple of years ago when I was leaving a Cleveland hotel and was being assisted in loading my baggage into a waiting car by the doorman, a large and powerfully built black man with a fetching smile.

Noting the scout pin in my lapel, he remarked, "I was a scout 22 years ago." He went on to point out with pride, "I am an Eagle Scout," to which I responded, "So am

I." He said, with obvious satisfaction, "I can still say the scout law." I assured him I could as well. Oblivious to the group of people standing around us on the curb awaiting their cabs, my new-found friend looked at me with a twinkle in his eye and decided to put me to the test: "Trustworthy", he said! "Loyal", I responded. "Helpful", he replied. From there on we sort of continued together, "Friendly, courteous, kind, obedient, cheerful, thrifty, brave, clean and reverent."

When we finished, the crowd on the curb burst into applause! As we shook hands to depart, I realized that this man was an instant friend simply because he had been a scout 22 years ago—and I one some 56 years ago.

The newspapers are fond of referring to wayward souls who have strayed from the beaten path by noting, "He is no boy scout." One of the finest compliments I can imagine anyone could pay to me is to say, "He is a boy scout".

And I know . . . because I am also a rocket scientist!

STEM CELL RESEARCH

HON. CAROLYN B. MALONEY

OF NEW YORK

IN THE HOUSE OF REPRESENTATIVES

Tuesday, February 29, 2000

Ms. MALONEY of New York. Mr. Speaker, Daniel Perry, with the Alliance for Aging Research, contributed an important article on stem cell research and ethics to the February 25, 2000 issue of Science. I submit it for the RECORD and urge my colleagues to read it carefully.

PATIENTS' VOICES: THE POWERFUL SOUND IN THE STEM CELL DEBATE

(By Daniel Perry)

Millions of patients may benefit from the applications of stem cell research, although there is disagreement about whether public funds should be used to develop the science. Patients have been key to winning political support. Acting as advocates, they have contended that public investment will speed the research and bring accountability to biomedical technology. A political dispute about the new research, which holds the potential for cures to devastating diseases and to foster healthy aging, shows the need to respect public sensibilities and to court public approval, as well as the importance of involving patients in debates where the methods of biomedical discoveries and ethical beliefs collide.

The achievement of isolating and growing cultures of self-renewing human pluripotent stem cells has set off waves of optimism among both researchers and the lay public (1). The promise is tangible for effective new approaches to incurable diseases and underlying biological processes (2). As shown in table 1, over 100 million Americans suffer from illnesses that might be alleviated by cell transplantation technologies that use pluripotent stem cells. Yet some representatives in Congress and some of the lay public, as well as religious groups such as the National Conference of Catholic Bishops, oppose putting public funds behind the technology. They say that stem cell research belongs under a federal ban that currently prohibits federal funding embryo research (3).

TABLE 1. PERSONS IN THE UNITED STATES AFFECTED BY DISEASES THAT MAY BE HELPED BY HUMAN PLURIPOTENT STEM CELL RESEARCH

Condition	Number of persons affected (in millions)
Cardiovascular diseases	58
Autoimmune diseases	30
Diabetes	16
Osteoporosis	10
Cancer	8.2
Alzheimer's disease	4
Parkinson's disease	1.5
Burns (severe)	0.3
Spinal cord injuries	0.25
Birth defects	0.150
Total	128.4

Data are from the Patients Coalition for Urgent Research, Washington, DC.

Per year.

PATIENTS FOR RESEARCH

In 1999, a coalition of three dozen national nonprofit patient organizations, the Patients' Coalition for Urgent Research (CURE), emerged to argue for public funding of human embryonic stem cell research under guidelines of the National Institutes of Health (NIH). This would achieve two goals: (i) participation by the broadest number of scientists under established peer-review mechanisms, thus rewarding the most promising research and speeding progress, and (ii) public accountability and guidelines developed through processes that allow for public comment on an area of science that has raised ethical concerns (4).

Why a patients' coalition? As taxpayers, patients and their family members are entitled to expect their government to make the most of a substantial public investment in biomedical research through the NIH and other agencies. And as the bearers of the ultimate burden when medicine cannot relieve their suffering, patients are the most compelling witnesses to the value of research that quite literally can save their lives.

In general, the patients and their advocates who are active for CURE display tempered optimism when it comes to appraising the chances of anyone's health benefiting soon from applications of stem cell research. Furthermore, broad views on the ethics and appropriateness of the technology have been expressed by those in CURE. For example, they believe in the principles of informed consent and free choice. Stem cell research must not lead to an underground black market in "spare" embryos for research. In addition, women and men, as individuals or as couples, should not be paid to produce embryos for research purposes.

The stories of patients and family members have fostered bipartisanship on Capitol Hill and have effectively complemented other activities such as the stance voiced by leading theologians from four major faiths—Roman Catholicism, Protestantism, Judaism, and Islam—who, noting the calls of their religions for compassion for the sick, wrote a joint letter to Congress urging federal involvement (5).

THE BROADER STAKES

The promise of human pluripotent stem cell research increases the likelihood that vastly more people will experience healthy and productive aging. Age-related disease costs billions of dollars and burdens millions physically and financially (6). The additional costs in medical and long-term care that are incurred annually in the United States because its Medicare recipients lose their functional independence are calculated at \$26 billion (7).

One can imagine the cost 20 years from now in the United States alone, when the

population over age 65 is expected to double and the number of Americans over age 85 is projected to quadruple (7). Unless bioscience engenders and receives broad popular support, in the future, nations like the United States, which have a rapidly increasing aging population, will more than likely struggle with a much greater health care burden. This is why it is so important to respect public sensibilities and to court public approval fervently, even though it is also public approval fervently, even though it is also likely that the next discoveries will, too, collide with the ethical and religious beliefs of some.

In the stem cell debate, patients have stepped forward to help draw the line between science in service to the community and science for lesser motives. Sadly, some

of their most compelling stories will be silenced before long by the progression of their diseases. It surely behooves us to remember their contributions and to engage their successors, who will continue to put a human face on the promise of biomedical research.

REFERENCES AND NOTES

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