Stem Cell Therapy for Post-Polio Syndrome
Edward P. Bollenbach, BA, MA, Professor Emeritus in Biology, Northwestern Connecticut Community College, Winsted, Connecticut

The media is abuzz with talk of stem cells, and there is hope of curing diseases, such as Parkinson’s and muscular dystrophy, and spinal cord injury, using stem cell technology. What about polio? It was delightful to see a press release from the Salk Institute this spring, which added post-polio syndrome to the list of targets for stem cell therapy.1

A refresher on stem cells
There are two broad types of stem cells with several subtypes:

EMBRYONIC STEM CELLS are derived from the human blastocyst — the result of five days of cell division after sperm and egg fuse into a fertilized egg (zygote). The human blastocyst is a sphere with about 30 stem cells inside, and these cells have many useful properties for therapy. Prodded with chemical messengers, they can develop into most of the cells of the adult body; i.e., they are pluripotent. In a lab dish, they can be maintained, dividing into new stem cells, for more than a year. They could easily be used for production of nerve cells or muscle fibers for post-polio therapy.

However, since the stem cells are not from the patient who will use them, they are easily rejected. This problem can be solved if the stem cells are cloned first by the patient donating a nucleus to a human egg cell and then allowing five days for development until stem cells are evident in the blastocyst. This is called therapeutic cloning or nuclear exchange. Therapeutic cloning requires new legislation and is currently not supported in the United States. Further, embryonic stem cells can transform into cancerous cells easier than the second type of stem cell, or adult stem cells.

ADULT STEM CELLS exist in many parts of the body, such as in the bone marrow, brain, blood, muscle, and internal organs. They are difficult to isolate because, in comparison to the tissue they are within, they represent a very small fraction of cells. However, many adult stem cells are pluripotent and can be prodded to develop into muscle, nerve, skin, and a variety of cell types. Because the patients can provide the stem cells for their own therapy, the stem cells are not rejected. Adult stem cells are not as prodigious as embryonic cells and cannot be maintained in the lab as long. Theoretically, as the technology progresses, adult stem cells should be able to serve as cellular material for new nerve cells and skeletal muscle fiber. (See Figure 1.)

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The Research Fund of Post-Polio Health International (PHI)
Some procedures may require embryonic stem cells and others may do better with adult stem cells. In the United States, there are currently very few samples of embryonic stem cells available, which government grants can fund. The American Medical Association (AMA) recently lobbied to have this reconsidered. No news yet.

Challenge for use in old polio

Old polio presents several challenges that are different from the disorders usually discussed as targets for stem cell therapy. For example, in a spinal cord injury there is a loss of cells at the break in the spinal cord — where the body of nerve cells resides. Outside the cord, each cell projects into a long tube, sometimes three feet or more, which ends at a muscle fiber within a muscle. Theoretically, these long tubes, or axons, end with a few branches that connect to the muscle cells. In a spinal cord injury, these fibers and axons within the peripheral muscles usually remain intact. What needs to be done is to connect a new nerve body with the axon already there.

In post-polio syndrome, it is the end branches of the axons that are dying off while the nerve cell itself may continue living or eventually die. If scientists successfully implant new nerve cells in the anterior horn of the spinal cord, can the cells extend axons and connective end branches out through the tissues to a target muscle fiber? In polio, once muscle fibers have lost their nerve connections, they struggle to survive. Muscle fibers typically will atrophy and become non-functional after losing nerve stimulation. Therefore, muscle fibers may also need to be replaced. This is much more difficult than implanting new nerve cells in one place such as in Parkinson's disease or spinal cord injury.

Yet, there are things that can be done. For example, new nerve cells or support cells can be implanted to either fuse into existing weak motor nerve cells or provide protective chemicals for support. This would allow existing motor nerves to function longer and possibly even sprout more.

Another approach may be to try to strengthen muscles closer to the spinal cord. Muscles such as the paraspinal or hip muscles, if damaged, can result in more disability than more distant muscles, like the calf. So it may be possible to have a positive impact on muscles at or above the hip, where they cause the most disability if weakened. Regardless, there are several promising approaches, including the use of scaffolding biological materials, such as chondroitin, to guide new nerves to their targets.

Several signaling factors act between stem cells, allowing them to differentiate and grow in the lab or in the body. As stem cell research progresses, more of these growth and differentiation factors for cell specialization, adaptation, and connection should be uncovered.
Looking ahead

Imagine a combination of mechanisms (some of which are already known) that can signal motor neurons (nerve cells) to form connections with new muscle fibers. Muscle signaling cell adhesion molecules (CAM) can attract the placement of nerve synapses (connections) to muscle. Without even using stem cells, new derivative cellular chemicals can guide cells to the proper muscle fibers in a trouble area. There are many other possibilities. The only question is how long will it be until effective therapies emerge from stem cell research.

Much of the advancement in stem cell therapies and much of the realization of future promise will come as a result of lab work using model organisms like mice. A model of spinal cord damage, resulting in complete paralysis, has been mitigated in a rat with neurons derived from mouse embryonic stem cells. After treatment, the rat was able to use its hind legs in walking motions whereas prior to treatment it could not.5

Rodents can be easily engineered genetically and cloned, without implanted cell rejection. Using a mouse as a polio model (Polio Network News, Vol. 18, No. 4), there is a new opportunity to study post-polio rehabilitation with stem cells. The possibility of using this polio mouse model for stem cell studies involving polio is clear, due to the success in using rodents to further the understanding of cell differentiation and the possibilities of stem cell therapy.6

The most vexing problem for polio survivors may be the speed at which stem cell therapy advancement occurs. The clock is ticking. If rapid advancement in the use of this technology occurs in the next ten years or so, those who had polio in the ‘40s and ‘50s may benefit. If not, these polio survivors may just miss the next milestone in medicine — the ability to regenerate muscle and nerve tissue.

So close to the remedy, and yet so far. ●

References

Edward P. Bollenbach (edwardbollenbach@snet.net) received a BA in Biology and an MA in Biology from the State University of New York at New Paltz, New York. In his professional work, he focused on bacteria and fungi, and, as he began to experience polio's late effects, he decided to use his scientific knowledge to clarify information about post-polio syndrome.

Rotary International: 
Dedicated to Eradicating Acute Polio
Michael Abdalla, MD, Orange, California

For the past four thousand years, the tiny poliovirus has killed and disabled millions of children. Today, we are on the threshold of eradicating poliomyelitis, a frightening disease that historically has been the world’s greatest cause of disability.

Rotary International (RI) initiated the effort to eradicate poliomyelitis in 1985, when it launched its PolioPlus campaign, the first and largest internationally coordinated private sector campaign in support of a public health initiative in the history of the world. By 1988, Rotarians had contributed $247 million to support the effort to eradicate only the second disease in history — the first being smallpox. That accomplishment and early victories over the disease in Latin America served as the catalyst for the 166 member countries of the World Health Assembly to set the goal of eradicating polio worldwide, with total certification by 2005.

RI has been the leading private sector partner in the global effort to totally stop the transmission of the poliovirus. Rotary’s commitment of $500 million and leadership of ten million volunteers has helped to reduce the number of cases of polio from 350,000 in 1988 to 2,000 at the end of 2002.

During that time, the number of countries harboring the wild poliovirus has been reduced from 125 to 7. But as long as there are new cases of polio anywhere in the world, every country is at risk. The virus is only a plane ride away and is not asked for its visa.

Three major challenges confront RI and its collaborators.

1. Continuing to achieve cease-fires. In November of this past year, health workers carried out a National Immunization Day during a cease-fire in Afghanistan.

2. Maintaining political will to finish the job in the face of a rapidly disappearing disease.

3. Ensuring funding to buy oral polio vaccine and get it to the children.

The World Health Organization (WHO) and UNICEF estimates that $1 billion is needed in the four-year period (2002-2005) leading to an acute polio-free world. Governments and other private sector sources have pledged $725 million of that sum, leaving a $275 million funding gap. Each year of delay in reaching the last child can add more than $100-150 million to the total cost of the program.

The remaining endemic countries include some of the world’s poorest countries. They need financial help to buy oral polio vaccine, to deliver it house-to-house, and to establish the surveillance systems that pinpoint the remaining pockets of the disease.
Filling the funding gap

Twenty months ago, RI set a challenging goal of raising $80 million from Rotarians in communities all over the world, during the period from July 1, 2002 to June 30, 2003.

Rotarians surpassed the $80 million goal and have raised or committed $111 million. More than $12 million was raised in the US West Coast region alone. The money will be significantly multiplied through a partnership with the Bill & Melinda Gates Foundation and through World Bank loans.

Observing the results

Many Rotarians travel at their own expense to wave banners and walk in parades and to stand in market stalls and public buildings to mobilize parents to bring their children in for immunization. They visit garbage dumps and slums and hike to remote villages to put drops in children's mouths, so not one child is left out.

"It was one of the great experiences of my life," says Anil Garg, an Indian immigrant and a member of the Rotary Club of Simi Valley, California, who organized 36 people to go to India. "There were 2.6 million volunteers, 100,000 of them Rotarians, in 650,000 booths who immunized close to 140 million children in two days."

WHO recently announced that there are now (2003) only six countries that are polio endemic and they believe that by the end of 2004 the world will have seen the last case of wild polio-virus infection.

The savings alone from not having to immunize children against polio in the future are potentially as high as US $1.5 billion per year — funds that could be used to address other public health priorities. Once polio is eradicated, the world can celebrate not only the eradication of the second disease in human history, but also the delivery of a global public good. Every person, regardless of race, sex, ethnicity, economic status, or religious belief, can benefit for all time from this accomplishment — no matter where they live.

PSA — Polio Survivors and Associates

Rotarian and polio survivor, PDG '92-93 Ray Taylor, Pinehurst, North Carolina, has received approval from Rotary International for a Health/Medical Fellowship. Rotary Fellowships are operated independently of Rotary International, and each fellowship has its own rules and administrative structure.

The purpose of PSA — Polio Survivors and Associates is to create a support and communications network of Rotarians, spouses, and associates who are either survivors themselves or are active participants in polio-related worldwide programs. They seek to assist individual Rotarians, Rotary Clubs, and Rotary International in all phases of their polio programs, including Polio Eradication, PolioPlus, Polio Partners, World Community Service, etc., by establishing an information and support network for survivors and through increasing the awareness of polio and the continuing condition and needs of polio survivors.

Rotarians, Rotaractors, or spouses are invited to become members. Associate members may be anyone with an active interest in the subject who agrees to abide by RI policies. All members must register with the Fellowship on the Internet, at www.taranto.com/mailman/listinfo/psa.
Last Christmas was the first time I said “polio” in front of our family friend, Raquel. Normally, I talk about my work in polio eradication until I am blue in the face. But Raquel is different. She is one of my mother’s oldest and dearest friends, and she was paralyzed by polio as an infant.

Raquel’s parents were determined to provide her an education and to encourage her through all of life’s adventures. I have known her my entire life but we had never spoken about her paralysis until this particular day. We spoke at length about her successes and challenges, and the potential legacy of polio eradication.

Three regions of the world are free of acute poliomyelitis: the Americas, the Western Pacific, and Europe. Polio is still endemic in seven countries (2002) and, of these, 99 percent of the cases are confined to India, Pakistan, and Nigeria.

In some countries like Angola, just ending a civil conflict can provide access to children who have never been vaccinated. It is a golden opportunity to talk to parents and communities about the importance of all vaccines.

By working at the community level, international non-governmental organizations (NGOs), such as CARE, contribute to the polio campaign from the bottom up. We motivate local leaders and train traditional healers and birth attendants to be our eyes and ears in the communities. Community surveillance not only helps the global effort to find and test every suspected case of polio, but also gives community volunteers a sense that they can make their families’ lives better despite the poverty in which they live.

Combating “volunteer fatigue” is one of the challenges of the eradication effort. In India, many people have been polio volunteers for years and still do not see the disease eradicated from their country.

Training volunteers to communicate effectively against rumors is another challenge. Fear of sterility, AIDS, and other diseases are just some of the reasons parents and grandparents do not allow children to be vaccinated.

We aim to eradicate polio this decade. Part of polio’s legacy will be a stronger global laboratory infrastructure, which will have the capacity to tackle other diseases.

When I next see Raquel, I will tell her about the conversations I have had with mothers in the developing world about vaccinating their children and the importance of taking their paralyzed children to rehabilitation centers.

Raquel’s strength keeps me motivated. I someday hope to tell her that polio has been eradicated — that no other child will be paralyzed by polio.
From the Editor...

Joan L. Headley, MS, Executive Director
Post-Polio Health International

Over the last 16 years, I have connected many polio survivors with many Rotarians and, last July, I spoke to the Rotarians in Johnstown, Pennsylvania. Here are my comments:

I had polio at 13 months, in 1948, and did not give it much thought most of my life. My first memory is during Halloween. It was tradition for the kindergarten class to dress up and parade through the other classrooms. My mother sent me to school with my clown outfit and mask, and when it was time to put on my costume, I refused. You see, I thought it was silly for me to walk around in costume. Everyone would know me from my limp. My teacher finally collected my sister, Karen, from fourth grade to help persuade me to participate. She succeeded, with comments about embarrassing the family. That day, partly because I loved my teacher Miss Fawn, I decided that it must not be important how one walks, and I have carried this idea with me all through life.

Susan has spent every night since she had polio at a young age in an iron lung. For the majority of her life, she frog breathed during the day. Several years ago, she called me to say she had been out to eat, with the assistance of her attendant, and had to make a choice — eat or breathe. She couldn’t do both at the same time anymore. Today, she uses a ventilator full time. She has the portable ventilator on her chair, with the mouthpiece attached in place with Velcro, so she can put her mouth on it and receive air. For her, staying in an iron lung all the time was unacceptable. There are movies to see, shopping to be done.

When I told her our new name — Post-Polio Health International — she told me she liked it. Quoting Susan, “People automatically equate having a disability with being sick. Maybe this new name will help correct that idea.” Barbara Duryea and her colleagues are also doing their part. I am in Johnstown to participate in a retreat coordinated by the Conemaugh Health System. Peter Jay and I are members of a team leading a seminar called “Healthy Living with a Chronic Condition.”

Larry who recently retired from his professorship sleeps each night with a ventilator. He spent time in rehabilitation and writes eloquently about being the child in the iron lung who was visited by other children who had re-learned to walk. No one ever stated it, but he knew he was being exhorted to “greater efforts and better spirits” by the “cruelty of comparison.” He retired as a Professor of Philosophy, has edited an encyclopedia of ethics, and has made peace with his polio experience.

Another friend, now deceased, became a wealthy man — certainly by the economic status of most of the world’s 20 million polio survivors — by creating and selling decorative ceilings. He, in telling his story, speculates that lying in an iron lung staring at the faceless hospital ceiling may have inspired him.

A Post-Polio Health International Board member, who has been in a continued on page 8
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wheelchair since her acute polio, graduated from college, but was refused a license to teach for “being a fire hazard.” She founded an organization to find solutions to the barriers she encountered and was instrumental in promoting the independent living movement in the early 1970s. For those of you who don’t know, independent living philosophy is the basis for the civil rights effort on behalf of people with disabilities, the cornerstone being the 1990 Americans with Disabilities Act.

She was appointed the Assistant Secretary, Office of Special Education and Rehabilitative Services in the Department of Education by President Clinton. Today, Judith Heumann is the Disability Advisor to the World Bank. Recently, in India, she assisted with giving polio drops to children and was equally moved as was your colleague, Donna Gambol, who shared her slides with our group last evening.

Judy, being a polio survivor, was also moved by the number of polio survivors she saw — those children and adults who did not get the drops and contracted polio. (See “Prevention still dominant response to disability,” below.)

Our mission at Post-Polio Health International is to enhance the lives and independence of polio survivors and home ventilator users through education, advocacy, research, and networking. We encourage networking at the grassroots level and know that there are collaborative projects with post-polio groups and Rotary International. For example, Rotarians have built ramps in Jamaica and paid for wheelchairs in Peru. A Rotarian, who is a polio survivor, is establishing a fellowship within Rotary International. (See box on page 5.)

Our belief is that the American, Western Europe, and Australasian experience of aging with polio can be instructive for all the world’s polio survivors. We are looking for ways to pass on this information without re-inventing the wheel, in culturally appropriate ways, and, as is the tradition and mandate of our organization, with input and advice of polio survivors.

We welcome the opportunity to network with you and all Rotarians around the world. Tell them about us, so we can expand our work together.

Lastly, I want to thank all Rotarians for the millions of dollars raised to cover the costs of immunizing the world’s children, and, as one who works for a nonprofit and knows the importance of people power, I would like to also thank all Rotarians for the thousands of volunteer hours which have accompanied the dollars to make this eradication effort a success.

Excerpt from World Bank International Dialogue on Disability and Development, Helsinki, May 29-30, 2003, Summary by Judith E. Heumann (jheumann@worldbank.org; www.disabilityworld.org/06-08_03/development/dialogue.shtml)
Dear Joan,

I write this letter to help some of our polio associates to know that it may take a serious gamble to improve one’s physical condition and mobility.

In mid-2000, my wife, Peg, and I moved to Florida from Missouri to be closer to our two sons. There, after nine months of physical therapy for a hip condition, my new primary care physician, a pulmonary specialist, referred me to an orthopedic surgeon. After reviewing my x-rays, he determined that I had a deteriorating condition of the entire right hip (including the lining) due to polio in 1937 at the age of 18 months. It seems that my abnormal gait and severe scoliosis, combined with years of baseball, softball, basketball, and hunting, had worn out my right hip and had severely affected my left hip.

The orthopedic surgeon felt I needed a more extensive hip replacement than he was comfortable doing, so he referred me to Robert T. Snowden, MD, in Pensacola.

Dr. Snowden felt that the right hip should be replaced as soon as possible and the left hip as soon as I had recovered from the first surgery. My primary care physician thought the surgery too risky for my weakened physical condition. In 1988, I had heart bypass (5) surgery and take medication (Cardizem and furosemide) for my heart. I use a BiPAP® ST, with supplemental oxygen, at night for restrictive and obstructive lung disease. But, my condition had deteriorated to the point where I had to use a wheelchair full-time, so I felt I had no choice but to have the hip surgery, and I insisted on it.

In March of 2001, my right hip was replaced with no serious side effects. Following eight weeks of rehabilitation with the help of Peg, my surgeon told me I could proceed with typical walking activities as best I could, but that I should use a cane for stability. When I returned for my three-month check-up, Dr. Snowden asked if I was ready for the second hip replacement. After taking all of one minute to think about it, I agreed.

In August of 2001, my left hip (which had completely deteriorated while I was going through rehab for my right hip) was replaced. Although, the rehab took longer for the second surgery, in three months, I only used a cane for support when walking outside and no support inside the house. (I do use grab bars in the bathroom.)

After the second operation, I had a total central vein occlusion (problem of getting blood to my left eye) and have had two vitrectomy surgeries resulting in a very slight improvement in my sight. I am able to read the letter “E” on the first line of the chart.

After two years of rehab, I am on my own walking anywhere I wish. I am almost free of pain except for minor sporadic arthritic pain, and, occasionally, I do become short of breath while walking due to my pulmonary condition. I regained a lot of strength, which I had been losing for the last 15 years. I reduced my glucose and cholesterol levels to the lowest they have ever been by paying attention to my diet and taking supplements.

I have not felt this good since 1985. It seems that polio can have potential devastating results over one’s lifespan, but, in my case, a gamble and my faith has allowed me to continue my life as I wish.

Your friend always,
Thomas Skinner (hunt671@bellsouth.net)

New Books — Reviews in next issue of Post-Polio Health

Postpolio Syndrome (ISBN 1-56053-606-3) by Julie K. Silver, MD, and Anne C. Gawne, MD, has been released by Hanley & Belfus (www.elsevierhealth.com). The book (336 pp.) retails for $29.95.

Breath: Life in the Rhythm of an Iron Lung (ISBN 1-878086-95-2) by Martha Mason is published by Down Home Press, P.O. Box 4126, Asheboro, North Carolina 27204 for a retail price of $24.95.
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Nobel Prize Winner Dies

Pediatrician and pioneer in the fight against polio, Dr. Frederick C. Robbins, died of congestive heart failure on August 4, 2003. Dr. Robbins, along with two colleagues, John F. Enders, PhD, and Thomas H. Weller, MD, won the 1954 Nobel Prize in Physiology and Medicine for their work in cultivating the poliomyelitis virus, an achievement that enabled the development and production of the Salk and Sabin vaccines.

Crucial to the development of vaccines for many other viral diseases including measles, mumps, and rubella, the culture method was most recently used to isolate the coronavirus responsible for severe acute respiratory syndrome, or SARS.
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REMIN DERS ...

It will soon be flu season. Remember to get your shot. The new FluMist is recommended for ages 5-49 and is NOT advised for people with chronic diseases and asthma.

Support Group Leaders:
The staff will be updating our Post-Polio Directory in late December. Please check your print and online entries and send any changes to Sheryl at webmaster@post-polio.org. Please confirm the group’s name, name of contact person, mailing address, phone, fax, email, website, and usual meeting month, day, and time (e.g., Third Saturday AM).

The Fall 2003 issue of Post-Polio Health features ...
Stem Cell Therapy for Post-Polio Syndrome
Rotary International: Dedicated to Eradicating Polio
Working Together to End Polio
... and more

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Post-Polio Health International
Including International Ventilator Users Network
4207 Lindell Boulevard, #110
Saint Louis, MO 63108-2915 USA
314-534-0475
314-534-5070 fax
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