For Optimizing our Lives

Recovery, Employment, Accessibility & SCI Research

By Eric A. Appleberry, DDS, MS

Not that long ago a spinal cord injury was, in fairly short order, a death sentence. That need not be the case now. Modern health care and other support structures of a modern society can provide people who experience this "tragedy" the opportunity to still have meaningful, enjoyable lives—in spite of SCI disabilities.

Yes, this life is, at the least, a more complicated one, and sometimes a very difficult one, but until we finally have the cure, it’s the one each SCIer is stuck with—and it is to our advantage to try to make the best of it.

In this Issue

There are two personal stories about women who have SCIs. The first is about the injury and recovery of Rhonda Elliott, who has managed a transition into meaningful work at the Monroe Center for Independent Living while still carrying on in her so very important role of being a mother, giving love, support and guidance to her two growing children.

The second is about Elaine Demps, 1st Runner-Up in this year’s Ms. Wheelchair of Michigan pageant, who at the time of her injury had a “personal coaching” business for helping others solve life problems. After her SCI she was able to apply those coping skills from her coach training to her own recovery—and re-establish her business.

And there are two articles about getting to meaningful employment. The first of these is about the help available from federal, state and private agencies for getting that satisfying, individually right type of work that can be sustained—often not an easy task, but rewarding when accomplished.

The second is about our local Ann Arbor Center for Independent Living and the wonderful workshop series they have on job skills and networking to find that “right job.”

The quality of the employment programming at the AACIL has been recognized by their having been awarded a multi-year federal support grant.

There is an article about getting prime seating accessibility for wheelchair people at the U-M football stadium—one of the most enjoyed sports arenas in southeast Michigan. The Michigan Paralyzed Veterans of America under the guidance of Executive Director Mike Harris got the University of Michigan to substantially increase the amount and quality of accessible seating in its renovation of the “Big House” U-M Football Stadium.

And there are two articles discussing SCI research developments since the lid came off of stem cell research (hopefully this will eventually lead to the cure: full functional restoration of spinal cord injuries).

The first article discusses President Obama’s lifting of the ban on stem cell research and Dr. Wise Young’s new clinical trial for the treatment of chronic spinal cord injuries, with a brief discussion of the Geron Trial for the treatment of new injuries.

The second research article, part of the Ask the Doctor series, interviews Dr. Sean Morrison, Director of the University of Michigan Center for Stem Cell Biology in the new U-M Life Sciences Institute. Dr. Morrison discusses in greater detail both the lifting of the ban on stem cell research and the Geron clinical trial.

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Rhonda Elliott

A Meaningful Life after an SCI: Motherhood & Helping Others

By Eric A. Appleberry, DDS, MS

It was a Friday evening, November 22, 2002; Rhonda Elliott, age 32, had a night out, relaxing and shooting pool with her cousin at a club in Monroe, Michigan. At the end of the evening, her cousin, who was driving, got stopped for speeding. When the police came up to their car her cousin (with a prior DUI record) panicked and sped off.

Now in a high speed chase situation, Rhonda also panicked and climbed into the back seat for safety. But when the car hit some gravel and skidded around into a utility pole, she got thrown against the back window, cutting her scalp and peeling it back from the top of her skull. She also had a lung collapse, and worst, her T-5 vertebrae was shattered. “I was upside down in the back, could hardly breathe, couldn’t move my legs and thought I was dying.”

Rhonda was helicopter transported to a Toledo hospital where she had her lung re-inflated, her scalp reattached, surgery to stabilize her back and two months of inpatient rehab. This was followed up with eight months of outpatient rehab at U-M MedRehab at Briarwood, Ann Arbor. “It was all very hard on my family, especially initially. When I was first in ICU I looked such a mess that my still quite young kids weren’t allowed to see me—so they thought I had died,” Rhonda said.

The SCI played a part in the breakup of Rhonda’s marriage, too. When family and friends were around their concern naturally would be focused on Rhonda [not realizing that a spouse is also confronted with immense adjustments]. So he was not receiving the help and support he could have used. After three years they separated, but fortunately are still friends. He lives not far from her and continues to have a sharing, close parental role with their daughter and son.

An inaccessible home was another problem for Rhonda once she was out of the hospital. But the auto insurance from the accident stepped up and built, in the country outside of Dundee, a fully accessible home that allows her easier functioning from a wheelchair. For instance, the kitchen appliances and work surfaces can all be readily reached, making meal preparations a pleasure; good washer/dryer locations ease the management of clothing; and accessible table/counter tops facilitate Rhonda’s working with her children on their homework. Being able to continue with the day to day chores as well as caring for her children gives her a sense of accomplishment.

The remaining problem to solve was getting back to work again. Rhonda had always worked outside of the home but at the time of the accident her job at Detroit Metro airport, handling baggage for Northwest Airlines, wasn’t one that would fit well with wheelchair life. So back to school she went, initially at Schoolcraft College, in Livonia, and now continuing at the Monroe campus of Siena Heights University. Her study programs have been aimed at a career in social work.

Rhonda Elliott, with daughter, Amber, 14, and son, JR, 11

Two years ago, looking for an SCI adjustment support group, Rhonda contacted the Ann Arbor Center for Independent Living, which referred her to their branch in Monroe. There, inspired by all of the services the CIL provides, she started working as a volunteer—just so she could be involved in their mission of helping others.

Then last year, the Ann Arbor/Monroe CIL received a VISTA grant for Community Network Outreach work to help clients, many of whom are referred by Michigan Rehabilitation Services. Rhonda was hired and flown to Chicago for special training. She is now “on the job” at the Monroe CIL, working with individuals on whatever is the needed next step in putting their lives back together.

“Working with people at the Center for Independent Living gives me a sense of usefulness that feels good,” Rhonda says, “but still, some days my life can be pretty tough. I have, however, over the last six and a half years learned that I can be much stronger than I would ever have thought.”
Federal, State and Private Agencies

Help Available in Getting to Employment after SCI

By Eric A. Appleberry, DDS, MS

Bummer; your life plan just got whacked, big time. So what are you going to do now—just “surf the web” on a computer or watch TV and movies? While entertaining, ultimately this can be kind of an “empty” life, without much meaningful involvement with other people. Your fellow humans have much to benefit from you and work you can do. And, you have much to gain from your contacts with them, including importantly, that sense of usefulness that comes from work participation in our society.

So, you’ve done your basic SCI rehab and are medically able—what comes next in attaining employment? That greatly depends upon the circumstances of your situation.

Social Security Administration Benefits

If you have a prior work history, made payments into the federal Social Security system and are between the ages of 18 and 65 you should be receiving Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI) benefits. This will trigger a “Ticket to Work” (with a lot of explanatory information) being sent to you. This “Ticket” is essentially a voucher that you can use with qualified public agencies or private Employment Network (EN) organizations. They provide the comprehensive services that may be needed to help you get back to work. Extensive information and a link to lists of qualified ENs may be found at the Social Security Administration’s website: www.ssa.gov/work/aboutticket.html.

Michigan Rehabilitation Services (MRS)

Anyone whose disability interferes with getting/keeping a job can be assessed by a counselor to determine eligibility for MRS services. This can include people receiving Social Security disability programs (MRS is a qualified EN) as well as those with no prior work history at all.

MRS counselors work with their clients individually. If eligible, the next step is to decide on an employment goal that matches the client’s interests, aptitudes and capabilities (e.g., one’s injury level). Many considerations need to be explored. If previously employed, to what extent does the (SCI) injury interfere with continuing in the same job? What is the transportation situation? Are assistive devices adequate? Etc., etc.

To achieve the goal, the client and counselor then develop a plan outlining the steps needed for getting to a job—such as acquiring certain licenses, computer skills training, etc. (services from other ENs can be included, too).

As clients carry out the stages of their plan, MRS monitoring is standard—and a plan can be changed if that would be helpful. When the goal of finding the right job is reached, the monitoring continues for at least 90 days to be sure both employer and new employee are satisfied.

If clients are financially able, MRS does ask that they contribute to the cost of their rehabilitation program—but MRS does not deny services if this is not possible.

The local, Ann Arbor, MRS office is located at: 3810 Packard Road, Suite 170. Telephone: 1-734-677-1134. For MRS office locations across Michigan call: 1-800-605-6722 or visit its website at: www.michigan.gov/dleg and click on Michigan Rehabilitation Services.

Employment Networks (Private)

These organizations help all people with disabilities; they are “private” only in the sense that they are not federal or state agencies.

A premier EN in our local area is the Ann Arbor Center for Independent Living (CIL), 3941 Research Park Drive. Telephone: 1-734-971-0277; website: www.aacil.org. They also have a branch office in Monroe, at: 40 Roessler Street. Telephone: 1-734-242-5919. Please see full page 4 article on the Ann Arbor CIL’s employment programming.

So, somewhere amongst these organizations there should be a good start for you towards beneficial employment.

Another Job Factor to Consider: Time for Your “Non-Job” Activities

Like it or not, an SCI affects all aspects of one’s life, including the greatly increased amounts of time needed for personal care routines such as toileting, bathing and dressing. A regular, and sustained long-term, exercise program (considered to be vital for long term health of any SCIer) also requires considerable time.

And, if besides these routines, you’re also doing your own laundry, grocery shopping, cooking and cleaning of your home—all of which will take longer for an SCIer—you may find that, besides sleeping and your job, you have precious little remaining time.

Add in the occasional urgent medical situation (e.g., an appointment for a UTI) or something like a bowel “accident” [is there an SCIer who has never had this happen?] and your plan for a day really can be disrupted.

Thus, in considering your career goal, it may be beneficial to chose one which doesn’t require a lot of overtime and where an employer might understand your need for infrequent but necessary short notice absences. Your MRS counselor or the folks at the Ann Arbor CIL may be helpful regarding this concern.
Ann Arbor Center for Independent Living

Job Search Resources—and an Understanding of SCI

By Helen Ledgard

Now, more than ever, the search for employment can be challenging, frustrating, and filled with hard work. And anyone who has an SCI knows that the challenges that come with this make the tough task of finding a job even more difficult. The Ann Arbor Center for Independent Living (AACIL, CIL or just “Center”) has a team of staff members, including one who has an SCI, who run an employment program. It is designed to help people with various disabilities gain the skills and know-how to conduct a strong and effective job search.

The Ann Arbor CIL job seekers program is multifaceted:

- Group workshops on search related topics of identifying the "right job" and how to find it;
- A job-seeker peer support, collaboration, and networking group called the “Career Team;”
- Individualized assistance to help job seekers tackle particular needs related to their career interests or specific disability-related challenges;
- Training on “soft skills”—the unspoken rules of work culture dynamics and expectations;
- Assistance to employers about disability-related employment topics.

Job seekers enter the program by participating in one of two group workshops. They have become quite popular since the Ann Arbor CIL began offering them in December, 2008. Participants speak highly about the information and networking benefits they get from these classes which are taught by Edward Wollmann and Molly Concannon.

One of the workshops, “Do What You Love!,” has three parts to help participants: 1) identify their transferable skills, 2) find their ideal work environment, and 3) discover their true career motivators and passions. This workshop is ideal for people who have been looking for a job for a while and need a new approach to identify their skills, qualifications, and career interests. It is also great for people who want to change careers or explore a new direction for their work life. After a recent workshop, one participant wrote, “This workshop was an awesome experience. The facilitator was great. The systematic process used to clarify my skills really helped me focus. And networking with the other participants was invaluable.”

The other workshop, “Networking: It’s as Easy as PIE,” is a three session course. As the name suggests, it is about networking. The importance of this cannot be overstated. It is a fact that most job openings are not advertised—they are found through networking. It’s simply not enough these days to apply for a job online and hope to get a call. But to many, “networking” is an intimidating concept: “I just don’t know anyone!” people say. This workshop is designed to tackle this obstacle. The class teaches an easy-to-learn, step-by-step process for making new connections, talking with employers and developing a network of contacts to help you land the job you want.

After participation in these workshops, clients are invited to join the AACIL’s Career Team, a peer support, collaboration, and networking group for job seekers. In the Career Team, job seekers practice what they learned in class, brainstorm together, share networking ideas, and give each other feedback and encouragement on the job search process.

Staff members can also work with job seekers individually to help them with specific career search needs. These include resume assistance, interview coaching and particular disability-related challenges a person may have.

The Center also offers a workshop on what are known as the “soft skills” of employment. Each workplace is a human environment, with expectations, dynamics, and a culture of its own. Being successful on the job requires adherence to the “unspoken” rules of work, keen interpersonal skills and adept problem solving capability. This workshop helps participants develop these competencies.

The CIL hopes to expand all of its workshops for online use so that people with mobility or transportation challenges can access the curriculum.

Additionally, the Center is a resource for area employers. Tom Hoatlin, Director of Development, leads the outreach effort. “At the CIL we offer many programs and events for employers, covering disability and employment related topics,” Tom said. “Through these activities we develop strong relationships with them. When job seekers have interests that match up with some of these employers, we make a connection. Sometimes just an introduction makes a big difference.”

The employment programming at the Ann Arbor CIL is funded collaboratively, including in large part by a multi-year grant from the U.S. Department of Education’s Projects with Industry program, which recognized the quality of the AACIL’s activity in this area.

For upcoming dates of workshops, please visit our website, www.aacil.org. For more information, or to sign-up, contact Helen Ledgard at: helen@aacil.org or phone: 734-971-0277 ext. 24. CIL workshops are free, but a small fee to cover a week of supplies and refreshments is asked, if a person is able to pay.
Insights and Information for People with SCI

U-M “Big House”
Prime Accessible Seating Created at U-M Football Stadium

By Michael Harris, Executive Director,
Michigan Paralyzed Veterans of America

In the true spirit of the Americans with Disabilities Act of 1990 (ADA), more fans with and without disabilities can now watch games live from a good vantage point in the “Big House,” the University of Michigan (U-M) football stadium. This is because wheelchair using football fans now have access to prime stadium locations.

The ADA outlines wheelchair-accessibility requirements for buildings. However, the proper way to interpret and implement its guidelines was not well established, especially with regard to structures built before the Act was passed.

Thanks to the Michigan Paralyzed Veterans of America (MPVA), the University of Michigan was successfully influenced to take greater consideration of ADA guidelines when expanding its football stadium. As a result, the University has added much more wheelchair-accessible seating and parking spots, and has also updated stadium facilities to bring bathrooms and ramps into compliance with the ADA.

Prior to these changes, the stadium had 81 pairs of wheelchair and companion seats, all located in the end zones. Last season, U-M added 96 accessible seats on the east side of the stadium in row 54, each with a companion seat. By the 2010 football season, 24 more wheelchair seats will be added in the student section and 56 more will be added on the east side in row 72. U-M will also include wheelchair seating in the luxury boxes and suites that are part of their expansion plan. In all, Michigan Stadium will have 329 wheelchair seats and 329 seats for their companions.

The U-M Stadium plan, which is both comprehensive and substantial, will now serve as a compliance model in regard to ADA guidelines when altering existing structures. This is a landmark case with national implications.

The Michigan PVA worked very hard to make the Michigan Stadium more accessible. All who participated in this process, including the U-M and mediators, should be commended for their hard work and determination. Because of these collaborative efforts, more fans with disabilities, together with their families and friends, will be able to enjoy first hand the excitement of home games.

Now it is important for people with disabilities who use wheelchairs to purchase game tickets to support the expansion and to show that the supply of wheelchair seating is not greater than the demand. And, U-M has agreed to waive the usual “priority point program” requirement for the initial purchase of preferred area seats during the first two years of their availability. (So let’s get going on this!) If you have any questions or would like to purchase tickets please call Marty Bodnar at 1-866-296-6849 or email him at: mbodnar@umich.edu; also check out the website: http://www.mgoblue.com/tickets/article.aspx?id=111482
The Stem Cell Promise for People with SCI: An Update

Stem Cell Research News
By Linda Spencer Berlin, MSW

The End of the Stem Cell Research Ban
As you probably already know, in March 2009, President Obama signed a new executive order that ended the 2001 ban on federal funding for stem cell research. In addition, Mr. Obama’s economic recovery package includes $8.2 billion in new tax dollars for health research.

These changes offer renewed hope for people with spinal cord injuries and their families because it will allow research on hundreds of stem cell lines already in existence, and allow new ones to be created from any embryos that would otherwise be discarded at fertility treatment centers. Many people believe that stem cell research may hold the key to better functioning or even to a cure for spinal cord injuries.

Because universities are the traditional sources of fundamental breakthroughs in medicine and discovering new medical treatments, they will likely play a much larger role in stem cell research, now that the government has eased the funding restrictions.

The University of Michigan is not currently involved in stem cell research for spinal cord injury. However, it does have a new embryonic stem cell research consortium, whose top priority is to create and examine human embryonic stem cells lines that carry the genes responsible for inherited diseases. These cell lines will be used to probe the causes and progression of disease, and to find treatments for diseases such as ALS (Lou Gehrig’s disease), Huntington’s, Alzheimer’s, and diabetes.

Wise Young: Another New SCI Trial
Dr. Wise Young, known as an outstanding neuroscientist and a leader in the field of spinal cord injury, spoke at Detroit’s Wayne State University in May of 2009 about the formation of the Spinal Cord Injury Network USA (SCINetUSA) in March 2009. This network is affiliated with the China SCI Network, which was formed in 2004 to test promising therapies.

Based on good results with animals and with people in preliminary Phase 1 & 2 trials in China, Phase 3 multicenter testing of two “promising” therapies, to hopefully restore some function in people with chronic spinal cord injuries, will take place in both China and the U.S.

One therapy involves transplanting “matched” human umbilical cord mononuclear blood cells directly into the spinal cord, just above and below the level of injury. In rats with spinal cord injuries this therapy improved their locomotor (walking) recovery.

The other therapy is using the drug lithium, which in rat studies has been shown to help spinal cord blood cells multiply faster and produce “neurotrophins” that stimulate spinal cord regeneration.

In China’s Phase 3 chronic SCI trial, all people will receive the matched umbilical cord blood cells and randomly half of them will also get the lithium.

In the U.S. Phase 3 trial (as in China), half of those getting umbilical blood cells will also get lithium and all of these will additionally get best current therapy (intensive outpatient rehabilitative training). And, a third group will get only this intense training (re: FDA requirement for also a “control” comparison to the best current treatment).

Several U.S. hospitals have already agreed to join the study. At present, the trial is only including subjects aged 16-60 with complete traumatic injuries, levels C5 to T10. They hope to obtain approval from the FDA by summer 2010, when they plan to start the treatment phase of the trial. Recruitment will begin in the fall of 2009.

For more information on SCINetUSA, check out their website at: http://nascinet.org.

Wise Young’s Care Cure website, with more information about clinical trials, is located at: http://sci.rutgers.edu/

Geron: A New Stem Cell Trial for People with SCI
In January 2009, a privately-funded California company, Geron, announced that it had received approval from the Food and Drug Administration (FDA) to begin the world’s first experimental study based on human embryonic stem cells to treat spinal cord injuries.

Geron’s technique has already been successful in producing significant improvement in rats with spinal cord injuries. When neural cells made from animal stem cells were injected into a rat’s spinal cord injury site, it recovered significantly in the ability to move and bear weight.
Insights and Information for People with SCI

Ask the Doctor

What does Stem Cell Research Mean for ME?

By Sean J. Morrison, PhD

Sean Morrison, PhD, a faculty member of the UM Life Sciences Institute, is Director of the U-M Center for Stem Cell Biology.

We asked him to address the following questions:

1. What does the change in the Obama administration mean for stem cell research in spinal cord injury here in the USA? What does this change mean for me?

In March, President Obama signed an executive order ending President Bush’s restrictions on federal funding for embryonic stem cell research. He directed the National Institutes of Health (NIH) to draft a new policy. Their draft policy would make NIH funding available for research with any embryonic stem cell lines that were derived according to a long list of ethical standards (contained in the draft policy). NIH collected public comments on this draft policy and the guidelines were made effective on July 7, 2009. For details go to: http://stemcells.nih.gov/

This policy is expected to dramatically increase the number of stem cell lines available for federal funding. Currently, no more than 21 lines are available for study with federal funding. Under the revised policy, we expect that hundreds of lines will be available, though the details depend on what changes are made to the policy during the comment period.

The draft guidelines represent an important step forward that will accelerate critical medical research by giving scientists access to more embryonic stem cell lines that better reflect the diversity in our society, make it possible to model inherited human diseases, and reduce the contamination of lines with animal products. Given the importance of human embryonic stem cell research to future medical progress, these draft guidelines will accelerate efforts to identify new treatments for major public health problems. Spinal cord injury research will benefit as researchers will be able to develop techniques for the derivation of spinal cord cells from a wider array of lines, including from lines that are less contaminated by animal products than existing NIH-eligible lines. This could lead to advances that could enhance cell therapies for spinal cord injury.

The president’s action holds special significance in Michigan. In November, 2008 Michigan voters approved Proposal 2 – loosening restrictions on embryonic stem cell research in the state -- over the objection of opponents who claimed there would be no funding to support this research. President Obama’s executive order means that the federal government will invest millions of dollars in new embryonic stem cell research. The passage of Proposal 2 means that Michigan scientists will be able to compete for this funding. I expect this will lead to millions of dollars in new federal research funding at the University of Michigan. These two landmark changes will allow world-class scientists in Michigan to devote their full talents to the search for new cures using stem cells.

2. What is the importance of the Geron trial in the next step of finding a meaningful cure for spinal cord injury?

The Geron trial, approved in January by the U.S. Food and Drug Administration (FDA), is a significant milestone for stem-cell research in general, and potentially for the treatment of spinal cord injuries. The FDA’s approval clears the way for the world’s first test in humans of a therapy derived from human embryonic stem cells. This trial will focus mainly on the question of whether it is safe to transplant cells derived from embryonic stem cells into patients after spinal cord injury.

So far, Geron has extensively tested their therapy in rodents, where it has appeared to be safe. If it is also safe in humans, this will accelerate all future cell therapies involving embryonic stem cells. If safety problems are identified, scientists will have an opportunity to learn from what goes wrong in this trial to improve future trials.

The current trial will be limited to patients who have had spinal cord injuries no longer than a few weeks prior to the trial stem cell treatment. Thus patients with older injuries will not be eligible for participation in this trial. It will take some time to evaluate the safety and efficacy of this stem cell treatment in recently injured patients before doctors and scientists will be able to assess whether the cells might benefit patients with older injuries.

In the safety trial, Geron will also be watching for any evidence that their therapy enhances recovery after severe spinal cord injuries, though this trial is not designed to definitively answer that question. If the therapy proves to

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Elaine Demps, 1st Runner-Up, Ms. Wheelchair Michigan 2009
By Eric Appleberry, DDS, MS

Elaine Demps, 60, was named 1st Runner-Up, Ms. Wheelchair Michigan, 2009, in the pageant held at Aquinas College, Grand Rapids, Michigan, in February of this year. Not a beauty pageant, Ms. Wheelchair America was created as a non-profit organization to recognize the spirit, endeavors and achievements of women who just happen to use wheelchairs.

With a college background in secondary education and broadcast journalism, Elaine had a career with the State of Michigan that spanned many roles: Public Information Specialist, labor relations, employee training and motivation, and program management. She also used this background to establish her own business in personal coaching, Bravo. She also is a dispute resolution mediator. Elaine additionally belongs to Toastmasters International and has earned advanced certifications in that organization.

Afflicted with rheumatoid arthritis since age 24, Elaine has had numerous surgeries to repair damage to her joints. It was during such an operation in 2003, to correct vertebrae instability at C1/C2, that her (incomplete) SCI occurred.

Elaine credits modern adaptive technology and coping skills gained from her coaching training for her ability to recover and restart Bravo, her coaching business (she can be reached at: BernJr@aol.com, Tel. 517-580-8872).

Elaine was in part sponsored for the Ms. Wheelchair Michigan 2009 pageant by the U-M SCI Model System.

Ask the Doctor, continued from page 7

be safe in the first trial, a second trial will be designed to carefully test whether the therapy is beneficial to patients.

The road to new cures is long and can be fraught with setbacks. It is not clear whether this current effort by Geron will succeed in improving the treatment of patients with spinal cord injuries. However, we are certain to gain new knowledge from this trial that will inform our thinking about the clinical use of embryonic stem cells and that will improve future therapies.

3. What should I do at this time? Who should be involved in a trial?

For now, Geron will only be enrolling newly injured patients in their trial. Patients must have a functionally complete thoracic (T3 to T10) injury 7 to 14 days prior to stem cell transplantation. For information, go to Geron’s website: http://www.geron.com/grnopc1clearance/

Results from this trial will be required before it will be possible to assess whether this approach to therapy is beneficial to patients and which patients should consider this therapy. Years of additional research will be needed, but at least clinical tests have begun with patients.