

THE VIRGINIAN

SERVING VIRGINIA & WEST VIRGINIA

VIRGINIA CHAPTER NEWSLETTER

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FROM THE PRESIDENT

Joe Powers

The Future is Up to You

A freshman class in Civics 101 teaches that the first obligation of government is “to defend its citizens from all enemies”. High on that list of priorities is defense against foreign enemies; but close behind in priority is to defend its citizens against another enemy: disease and illness.

That defense unfortunately has recently been weakened by budget reductions to the National Institutes of Health (NIH) – the first time in 36 years!

Dr. Elias A. Zerhouni, M.D., the NIH Director testified May 1 on Capitol Hill that the “up and down” budget reductions resulted in the loss of continuity in research projects as well as the loss of scientific personnel. In a recent National Public Radio discussion with Dr. Arthur Garson, Jr., M.D., the Dean of the University of Virginia’s Medical School, he noted that only 10% of all research proposals submitted to NIH are now funded – where previously 20%-30% were funded. This impacts all of the most devastating diseases from Alzheimer’s and cancer to autoimmune diseases as well. This means that research projects, although merited, never get off the ground. Clinical trials must be scheduled serially, one after another rather than concurrently, thus lengthening – tripling or quadrupling the time for completion. Ultimately that results in “the status quo” – a continuation with present medications and therapies along with all their serious side effects.

NIH research support for autoimmune diseases now stands at about 2% of the NIH budget; MG research support is nearly infinitesimal at .000018% - if I remember my math

correctly that’s less than two ten thousands of 1%! Yes, the budget for MG did go from about \$2 million to \$5 million – but that does not buy you much in the way basic or applied research, nor will it result in better medications or therapies – it certainly does not put you on a glide path to a “cure”. As far as most of the other “rare diseases”, including nearly 80 different forms of autoimmune disorders, their support hardly appears on the radar screen – many are simply ignored.

In a previous editorial, the need for a “Marshall Plan for Medicine” was stated. That may seem totally unrealistic today in view of an annual Federal deficit approaching \$400 billion, to say nothing of a national debt measured in trillions. However, the next 25 years includes an aging population of “baby boomers” with their share of chronic diseases that will significantly impact the nation’s medical infrastructure: hospital capacity, medical/nursing schools able to train sufficient doctors and nurses, as well as the Medicare/Prescription Drug programs.

Without seeming to appear “melodramatic”, we all know we live in a dangerous world threatened by pandemics and bio-nuclear terrorism. Yet we have no “surge capacity” in our hospitals. There is an expected shortage of 250,000 nurses! Dr. Garson noted we already have a shortage of doctors in 14 states – not even taking into account the needs of 45 million uninsured Americans who essentially “do without” medical care.

Although the present Congress is not adequately investing in the nation’s research programs or medical infrastructure, there is funding available to do just that. In earlier editorials we’ve pointed out the apparent waste of nearly \$30 billion in “earmarks” – those special giveaways that members of both political parties use to curry re-election advantages and campaign contributions. That \$30 billion is the equivalent of the entire NIH budget! With life and death issues involved, its not “rocket science” to figure out that Congress has its

priorities all wrong. Re-examining programs known for waste – including tax cuts given to American companies that take their operations abroad at the expense of American jobs – are also opportunities to find sufficient funding that would be better used for improving our national healthcare system.

Just as government has an obligation to defend its citizens – as a right – that same Civics class also teaches that for every citizen “right” there is an obligation to participate in the process of government. For the average citizen that means being informed about the issues, forming their own judgment and voting accordingly. For the citizen with medical problems and the MG patient, it should mean joining with others to help build a more responsive medical system through a strong advocacy program; through increased research we’ll one day find better therapies – and one day “a world without MG”. Your chapter offers the opportunity to join with others in this battle for a cure. Your help is needed – it won’t happen without all of us pulling together. Can we count on you? The future is up to you.

Gene Variant Noted In MG

Scientists in California and Paris, working together, have noted a specific variant of a protein’s gene called PTPN22 that may contribute to the susceptibility of MG. The protein apparently serves a regulatory function for the immune system.

Reporting in the February ’06 Annals of Neurology and Muscular Dystrophy’s “Quest” magazine (May/June 06), the scientists evaluated 470 MG patients divided into two groups: those with a thymoma or titin antibodies and those without a thymoma tumor.

Of the 470 total number of MG patients, 293 or 62.3% had no thymoma; of this group, 80 patients or 27.3% registered the variant gene, PYPN22. The remaining number of MG patients – 177 out of the total of 470 – or 37.7% did have a thymoma tumor associated with their MG. This number (37.7%) is over twice previous estimates (15%) of

MG patients with thymoma. Of the 296 non-MG patients only 7.4% had the variant gene. As a result of their findings, the authors concluded that there are different levels of MG severity or expressions of the disease – or may in fact be more than one disease.

Source: *Annals of Neurology*, Feb. 06 and the *Muscular Dystrophy Association's Magazine "Quest"*, May/June 06. (www.mda.usa.org)

From the Program Director

Email Change: Please note that we have a new email address: PMBirckhead@earthlink.net.

MARK YOUR CALENDARS FOR SAT. SEPT. 9TH!!!

The Northern Virginia MG Support Group will be hosting the Fall Membership Meeting outdoors this year. Come join us for food, fishing, and fundraising. Picnic by the Rappahannock River under a covered pavilion complete with restrooms! The Northern Virginia Group will be creating several gift baskets that will be raffled off to raise money for the Chapter so your participation will be greatly appreciated and very much needed. If you would like to create a gift basket to raffle as well, it would certainly be welcomed. Fishing off the pier will be available. Make sure you bring your fishing pole, bait, and a current fishing license. Picnic tables are available, but bring lawn chairs for more comfort.

The festivities begin at 11am and we plan to eat around 1pm. If you can't arrive until 1pm, we'll be holding the basket auctions after lunch.

Let's come out and show support and to thank those that have been working so hard even through illnesses, to keep this organization together. We can take care of chapter business and have an enjoyable day as well. Family members and children are welcomed to join in the fun!

If you can, bring a side dish to share. Chicken, hotdogs, and hamburgers will be provided. For best directions do a map quest from your point of origin to 9320 Canvasback Court, Port Royal, VA 22535. If you do not have access to a computer, please contact me or

Phyllis. **Please RSVP to Anita Steele at 804/742-5149 or Phyllis Birckhead at 800/728-4405 or by email.**

West Virginia MG Support Group

Our MG friends in the "Mountain State" have been very busy. To celebrate National MG Awareness Month in June, they created flyers and distributed them in doctors' offices, clinics and hospitals to insure both doctors and MG patients know that the Support Group was there to help. That was a great idea – and they coupled it with getting more publicity with an article in the Princeton Times newspaper. **The WV Support Group usually meets the 2nd Saturday of each month at the Princeton Community Hospital in the Education Dept. The meetings begin at 1 p.m.**

If you would like a copy of the article or need additional information about where and when they get together, **call Karen Farmer at (304) 922-0393 or (304) 324-5852.**

To celebrate the 4th of July, they wore their red, white and blue for a great watermelon feast – and enjoyed each others company. So for those of you in the great state of West Virginia, don't miss out on the fun – join the Support Group, have fun, make new friends, and maybe even help some other MG patients!

Congressional Advocacy

ADA Continues to Lead!

Exceptional and effective leadership continues to be demonstrated by ADA – the Autoimmune Disease Association – in securing more Congressional support for autoimmune research. ADA sponsored a two day National Conference on Autoimmune Diseases this past spring. Held in Washington in conjunction with the annual Congressional Workshop and Congressional visits, awards were given to Sen. Joseph R. Biden (D-DE) and Sen. Richard C. Shelby (R-AL) for their leadership in support of autoimmune research. Former Secretary of Health and Human Services and former Gov. of Wisconsin was the keynote speaker.

For their continued leadership in supporting all autoimmune research, the Virginia Chapter salutes Dr. Stanley

Finger and Virginia Ladd of ADA, and particularly Abby Bernstein of ADA, Kathy Hammitt of Sjogren's Syndrome Foundation, and Bob Goldberg of the Myositis Association. Note Abby's and Kathy's patient histories on our webpage (still being built) at www.myasthenia-va.org. They are all "heroes" and "heroines". Thanks!

Funding for Federal Health Programs

Working directly with Congressional staff members on the Appropriations Committee, ADA submitted desired funding language for three federal agencies: the National Institutes of Health (NIH), the Centers for Disease Control and Prevention (CDC), and the Agency for Health Research and Quality (AHRQ).

Increased funding was requested for NIH to assure integrated autoimmune disease (AD) research. The accomplishments – and necessity of continuing – the work of the NIH Autoimmune Disease Coordinating Committee (ADC) was further highlighted in the Appropriations submission. The ADCC committee is responsible for the biannual publication of NIH's Autoimmune Research Plan. ADA and nine other patient advocacy groups actively participated in the work of the ADCC committee.

The CDC Appropriation language submitted directed funding support for programs to increase autoimmune disease awareness in the public and the medical community.

In the appropriation request for AHRO, a study was requested of the financial impacts of autoimmune diseases on the country's healthcare system and economy.

ADA's leadership, along with the active participation of the other patient advocacy groups, has primarily been responsible – in the Congressional endorsement – of seeing additional funding for the entire spectrum of autoimmune diseases. Although this funding level is substantial, it is still short by an estimated \$250-\$300 million. **Funding is available to support only 10% of all research requests submitted to NIH.**

NIH Re-Organization Supported

ADA continued to work closely with the staff of Rep. Roy Blunt (7th, MO) on

the NIH Re-Authorization Bill, specifically requesting an Office of Autoimmune Disease Research to be established within the Director's planned Division of Program Coordination, Planning and Strategic Initiatives. ADA also requested specific language encouraging trans-Institute autoimmune disease research that would benefit all autoimmune diseases.

Autoimmune Symposia Sponsored

The 8th Annual Autoimmunity Day sponsored by ADA was held at Johns Hopkins University in June, followed by a meeting of the Federation of Clinical Immunology Societies (FOCIS). The theme of the symposia was "Pathways of Autoimmunity from Genes to Pathogenesis".

Legislation Co-Sponsors Sought

A Congressional bill to support and increase a number of programs to increase awareness of and research on autoimmune diseases is being developed by Rep. Patrick J. Kennedy (D-1st, RI). Before the bill can be submitted and to assure passage, co-sponsors of the bill need to be secured, particularly from the Republican side of the aisle. If you think you can persuade your Representative or Senator to sign on as a co-sponsor, contact ADA at 1-888-856-9433 to obtain a copy of the bill.

Nurse Recovers From Medical Crisis and Medical Errors

By Bunny Medeiros

It was 7 AM on a Sunday morning. Opening my eyes and looking straight ahead to the light streaming through the curtain, I was perplexed. There was not one frame encasing the window but two. I closed my eyes again, reopened them, and still I was seeing double. Looking beside the window to my wall of family photographs, each picture had a second frame surrounding it.

I got out of bed and started moving around and, although this was a little dizzying, I adjusted to it and managed to get myself ready for a church service. I got in my car and decided I could drive safely around the little town where I lived but should probably not attempt to get on the highway. So, instead of going to my regular church, I attended a service in town.

At the service I learned there would be a pot luck later that day prior to a slide presentation by someone I knew who had just returned from Iraq. So I joined in later that evening and, while eating I found I had to drink more liquid than usual to swallow my food. I had had this experience several times before at very sporadic times and really paid no heed to it. The double vision had largely subsided throughout the day so I really was not concerned anything was truly wrong at this time.

The following day I woke and not only was the double vision more pronounced, but my eyelids were slightly drooping and my speech was now affected. I knew these were spelling out neurological symptoms so I decided I should see the doctor. I made an attempt to drive my car out of the carport but quickly realized this was not safe to do. I called my neighbor who kindly drove me to the doctor.

This physician had treated me for a sinus infection two weeks earlier with a drug called Ketek (Telthromycin). He was perplexed by my symptoms. Since Ketek is a new drug (on the market only 8 months before I took it the first time for a sinus infection one year previously in January 2005) and had obviously not read that much about the drug because the insert said right on it that it was "not recommended for people with Myasthenia Gravis." The doctor ordered an MRI which proved to be negative for stroke or brain tumor. By this time I was having pronounced difficulty swallowing and my speech was becoming noticeably slurred. Before ordering a neurological consultation, however, the doctor wanted to wait until the next day to see the results of the blood work he had drawn at his office and after learning they were all normal he decided to wait on the consultation and order another antibiotic and decongestant.

That evening two of my nurse practitioner friends came to my home to try to puzzle out what might be going on with my health. Being uncomfortable about spending the night alone, one of them decided to stay with me. The following day, my speech became more slurred, the double vision worse, and swallowing was near impossible. By

2:30 that afternoon, my friends agreed that I needed to go to the emergency room to be evaluated.

I had familiarity with Myasthenia Gravis, dating way back to my days in nursing school and had already begun to connect my symptoms with it. Although I never saw a patient with this disorder, I had seen one on a TV doctor program that all the nursing students gathered to watch each week. I couldn't recall if it was Dr. Kildare or Dr. Ben Casey who presented the case, but I remember to this day the face of the actor who was afflicted, eyes drooping from ptosis and weakened facial muscles. Out of all the cases I saw on those two programs over a three-year period back in the sixties, it seems so strange that this was the only one I have recollected.

My nurse friends had no information to share when I asked what they knew about Myasthenia Gravis, and the same was true of the friend, a health professional, who drove me to the hospital. The emergency room doctor diagnosed me with MG immediately but did not admit me. Instead he said the good news was it is treatable. I protested about not being admitted and said "I feel terrible." His response was that I would have to tough it out for fourteen more hours because I would not have the neurological consultation until morning. He left the examination room, called in his medical student and intern to come in to try to diagnose my condition, and I never saw him again.

The next morning the neurologist catalogued the possible diseases I might have, and settled on Myasthenia Gravis over Guillian Barre and Botulism. He asked me if I wanted to be hospitalized and when I said I thought I needed to be hospitalized he shocked me by saying he would admit me to the Intensive Care Unit. He drew some blood which, along with a second diagnostic blood test in the hospital, proved to be seronegative. The definitive diagnosis was based on the tensilon test administered in the hospital. I had little response to the IVG and the EMG and Nerve Conduction studies were both negative. I started the Prednisone on Feb. 4th and, after building up to 60 mg. a day along with

Mestinon every four hours my symptoms began to improve.

I was not, however, out of the woods yet because I had a major setback from an error in judgment by the ENT specialist, the pharmacist, and my own neurologist who all decided after evaluating my sinuses with a CT scan that it would be safe to give me Cipro. I was extremely apprehensive about being given another antibiotic because I was aware by this time that antibiotics are on the list of drugs as contraindicated or to be given with caution in MG. I felt strongly that Ketek was responsible for causing this medical crisis and I now believe that that it had, in fact, launched the MG after I took it in January of 05. The sinus infection had seemingly resolved but I developed what I believe was a yeast infection, marked by lower bowel dysfunction (alternating diarrhea and constipation with excessive bloating). I believe the yeast infection (Candidiasis) became generalized over time and turned into "Leaky gut syndrome." My immune system was further compromised from the prolonged stress I had been under for some years addressing the needs of my aging parents (long distance). Also, there were several times throughout the coming year that I experienced occasional episodes of difficulty swallowing food without a lot of liquid and sometimes struggling to swallow a large vitamin pill in the evening. The instances were so sporadic; I paid no attention to them.

After receiving two doses of the Cipro in the hospital and a third two hours after the second dose (a nursing medication error), it was clear that my symptoms were worsening again and soon my breathing became compromised. By this time I had a nasogastric tube for nourishment which was how my medicines were being administered. Over several days there was talk of putting me on a ventilator as well as switching the feeding tube to one that would be directly inserted into my stomach, a risky procedure since it required that I be anesthetized. In the end, I kept the NG tube, which had to be reinserted because the first one fell out, and, thankfully, my breathing did not

become critical enough to warrant being hooked up to a ventilator.

I got almost no rest or sleep the entire time I was in the hospital. There were constant procedures including, more CT Scans and blood work almost every day (to evaluate some abnormal liver values and investigate being positive for Hepatitis B), a Barium Swallow to evaluate my swallowing mechanism. There was respiratory therapy around the clock and physical and occupational therapy daily. Interruptions for checking my vital signs and changing out the feedings happened regularly. Sometimes a bed bath was worked in on the evening shift. I called in the nurses every two hours around the clock to re-position me because I was unable to move myself. With all the tube feedings and the intravenous fluids I needed to get up to the bathroom pretty regularly. It took two staff members to do this the first ten days of my hospitalization until the Prednisone and Mestinon began to have a more pronounced affect on my weakness. The most sleep I probably had the entire time was perhaps three one-hour doses during the night on one or two occasions. Normally I slept about an hour and a half around midnight and then often not at all the remainder of the night.

I cannot describe the degree of exhaustion and weakness I felt. I am convinced that the healing energy I received from friends, acquaintances and countless people praying for me in churches and homes everywhere are truly the answer to how I survived this medical crisis. I never stopped believing that I would recover. Even in the dark moments when I became scared, mostly at my having virtually no control of what was happening to me, I drew strength from the images of all the cards strewn across my wall and the small treasures of hope in the gifts on my windowsill.

Finally, after being in the hospital for sixteen days, my health insurance company decided they could not approve any more days. Because I still had the feeding tube in and people would have to be trained to continue that, it became necessary that I consider going to an assisted living facility.

Finally they approved five more days of hospitalization specifically for discharge planning. Three days before my discharge, the feeding tube became clogged and I refused to have it put back in. I had just begun swallowing ice cream, applesauce and other nutrition of similar consistency, which became infinitely easier without the feeding tube irritating my throat.

During the three weeks, I was distressed that the nurses knew next to nothing about MG. They did not seem to understand that I had no volition to move my muscles. I called the nurses in every two hours to reposition me and of course I had to be assisted to the bathroom (by two people the first week). Bathing was infrequent and mouth care was never offered. Communication between shifts was woefully inadequate which is how I got double dosed on the Cipro.

When I was discharged, I went to the home of some generous friends for 2 ½ weeks until I was strong enough to return home. I had in-home therapies during this time and my upper body strength began to progress quickly. The lower body strength took longer and is still not fully recovered whereas my upper body was back to normal in 2 months.

I had been unhappy with my neurologist and by the end of May had found a new one who agreed to begin reducing my Prednisone dosage. It has been uneventful thus far and I begin 30 mg/day in July. I continue taking Mestinon 60mg four times a day although I have been experimenting some with half the dose. I resumed my massage practice in April, gradually increasing the number of appointments and am able to see about half clients I previously saw which is eight or ten people a week. Some clients have remarked I am stronger than I was before and people constantly comment on how healthy I look.

I must, however, say that I look much better on the outside than I feel on the inside. The weather has quite an impact on how I feel; heat, humidity and the summer ozone levels create very unpleasant internal feelings. Concerning the emotional aspect of having MG, I must acknowledge that

my greatest challenge is in slowing down, having always been a high energy person involved in many interests. I do spend much more time at home and seldom go out in the evening even though I do not seem to be very fatigued in the evening hours. I continue to experience more weakness in the earlier part of the day. I am bicycling short distances and take two-mile walks regularly in addition to continuing physical therapy exercises. My lower body is becoming stronger and I have hope that I will never have another major medical crisis. My goal is to get off the Prednisone but I must admit the side effects from other drugs are also disconcerting. I am very focused on good nutrition and take an organic product that contains amino acids and probiotics to keep the Candida under control.

When I see pictures of me even one month after I got out of the hospital I am amazed at my own recovery. I like talking to others with MG to hear the stories of their onset, treatment and progress. It is certainly one of those diseases that seems to harken from another planet, and although the incidence is so small I continue to hear from many friends and acquaintances that they know someone with MG. I am still on the path toward more acceptance and try my best to dispel the fears about my future health and what limitations I may need to impose on my lifestyle.

I am still questioning some of the hospital charges. I have considerable bills due to co-pays in my Health Savings Account policy that my daughter was not informed of when she called to inquire about my coverage. Anthem confirmed I had a maximum of \$4000 out of pocket but my current charges exceed that by almost \$10,000.

But, for now, I am so grateful to have come as far as I have with what I believe has been a remarkable recovery, initially due in no small part from all who responded to me in my time of great need with prayers and assistance. Their efforts gave me strength and hope.

By Bunny Medeiros

NIH Steps Up Genetic Studies

A new initiative is being launched by NIH to fund the genetic and

environmental factors that lead to major illnesses, such as heart disease, diabetes, cancer and Alzheimers. A “peer group” of scientists will select the initial target diseases and patient populations. The project is being supported by a partnership between NIH and the Foundation for the National Institutes of Health(FNIH) and two pharmaceutical companies: Pfizer Global Research & Development of New London, CT and Affymetrix Inc. of Santa Clara, CA.

The project accelerates genome association studies to find the genetic roots of widespread sicknesses. The genetic analysis component of the two initiatives is highly complementary.

“Virtually all diseases have a hereditary component, transmitted from parent to child through the three billion DNA letters that make up the human genome”, said Francis S. Collins, M.D., Ph.D., Director of the National Human Genome Research Institute of NIH. Dr. Collins is also Chairman of the Genetic Association Information Network (GAIN) Steering Committee and Co-Chairman of the NIH Coordinating Committee for the Genes and Environmental Initiative (GEI).

Dr. Collins added, “But progress in identifying the genetic factors that influence health or disease, or even the response to treatment is difficult. Both initiatives promise to rapidly identify the myriad genes in an individual that, taken together, contribute to an increased risk of illness – or that increase the changes to a healthy life. As the genetic underpinning of health and common diseases become clearer, researchers will be empowered to develop targeted treatments that either prevent illness from occurring or treat it effectively once it does.”

The research will lead directly to the identification of major genetic susceptibility factors for common diseases of substantial public health impact.

Source: NIH News, February 8, 2006

A Nutri/Med Note

Keep Your Heart Steady

In November 04, the *Journal of the American Medical Association* noted that being really overweight is an important risk factor for arterial

fibrillation – in which the heart’s upper chambers quiver rather than beat steadily, potentially a fatal disorder. Now the journal, “*Circulation*” (July 06) reports that twice as many folks have an erratic heartbeat – some 5 million!

So to keep your life and heart steady, **think less**: less carbohydrates, sugar, salt, and fat-filled meat. Instead, **think more**: more fruits, veggies, green salads, fiber filled whole grain breads – and chicken or fish (no Big Macs!). And a round of daily exercise of some type (both cardio and resistance – 30 minutes) will help a lot as well. But check with your doctor first before starting any “diet” or exercise program. But do get started!

A Medicare Moment

The “Doughnut Hole”

If you’re about to fall into the Medicare drug “doughnut hole”, you’ll have lots of company. The “doughnut hole” is the gap in coverage from the Medicare Prescription Drug program and kicks in after you’ve paid the initial \$250 and 25% of the next \$2000 of drug costs or \$500. At that point, you’re on your own for 100% of drug costs from \$2000 to \$3600 – for a net increase in cost of \$1600! About 8% of Medicare recipients will encounter these additional costs this year – or about 3.4 million people. Or stated another way, the pharmaceutical companies will pick up another \$540,000,000 of your money.

Kelly Greene of the Wall Street Journal (encore@wsj) offers a couple of suggestions if you need help.

1. Check with your doctor and pharmacist to see if you can switch to lower cost generic drugs.
2. If your income isn’t too high, but above the Medicaid limit, you might qualify for an “Extra Help” subsidy from the federal government that could amount to \$1225/month for individuals. Check out the website benefitscheckup.org, to see if you qualify. If you need further help, you may call 800-424-9046 or go to www.accesstobenefits.org to

find a local group that is part of the "Access to Benefits" coalition.

A more permanent solution would be to request your Congressional representatives to change the Prescription Drug legislation that will permit the federal government to negotiate lower discount volume prices. Why pay exorbitant prices if you can get it at a discount? No doubt Congress had to reward the pharmaceutical companies for their political campaign contributions – and therefore patients have to pay the extra cost.

Israeli Researchers Close in On Vaccine for Autoimmune Diseases
By Allison Kaplan Sommer, 03/12/06
(The information in this article focuses on MS and other autoimmune diseases. However MG is part of the autoimmune family and this research effort could possibly impact MG.)

A revolutionary approach developed in Israel which uses the body's own cells as a vaccine for treating autoimmune diseases is showing tremendous potential in human trials.

The most recent trials are taking place at Sheba Hospital and Hadassah Ein Kerem Hospital, where MS patients are being vaccinated in hope that it will slow down the deteriorative effects of their disease. The results of the double-blind studies are expected to be released in coming months.

The trials are based on scientific research dating back 25 years to the laboratory of Prof. Irun Cohen of the Weizmann Institute. In 1981, Cohen and one of his students, Avraham Bin-Nun, first published their observations that the cells that trigger autoimmune diseases – called T-cells – can be adapted to vaccinate the body against their destructive action. T-cells are a subset of lymphocytes that play a large role in the immune response. The abbreviation "T" stands for thymus, the organ in which their final stage of development occurs.

"From my background in infectious disease and work with the measles virus, I became certain that you can teach the immune system to resist the agent that causes the disease," Cohen told ISRAEL21c. "In the case of these

conditions, that destructive agent is a member of the body's own immune system. By singling out the renegade element for immune regulation, you can turn a part of the immune system into an impediment to the disease. The concept was, in a way, a seminal concept because it said that the system can repair itself."

The initial findings, and subsequent successful trials using animal models, hold out hope for the entire range of autoimmune diseases from MS to arthritis, thyroid disease, lupus and diabetes. [And hopefully, Myasthenia.]

The 1981 finding, says Cohen, "was, in a way ahead of its time. The pharmaceutical industry back in the 80s and 90s only wanted to take medications and put them in a bottle. They did not think that a cell therapy, an individualized cell therapy, which could isolate cells and a vaccine, was something that could turn a profit."

This is the primary reason that Cohen's concept of T-cell vaccination stayed in the laboratory for so long. But in recent years, there has been renewed interest in his technique as "the whole concept of individualized therapy has become prominent."

An American company called PharmaFrontiers in Texas is also moving forward with T-cell vaccination research involving MS, diabetes and cardiovascular disease. In China, Cohen reports, scientists are focusing on arthritis and lupus with "promising results".

Cohen has taken it upon himself to organize regularly scheduled workshops – one as recently as last month – to bring all of these scientists from around the world together on a regular basis, and to "share ideas and strategy."

"I'm kind of the hub of an international community investigating how we can use T-cell vaccination in a number of diseases," he says.

Cohen is particularly excited about the multiple sclerosis trials currently underway. He takes pride in the fact that a former medical student who came to his laboratories to perform basic research approached him later in her career about conducting the trials in her facility. That student is Prof. Anat

Achiron, who runs the Sheba Multiple Sclerosis Center, where her team is preparing for the upcoming results of their current clinical trials.

More than 60 percent of Israel's 4000 MS patients are treated at the Sheba center. The center is a multi-disciplinary treatment facility – the only one of its kind in Israel – offering MS patients comprehensive treatment, from the earliest stages of diagnosis through preventative and rehabilitative care. All services are provided under one roof in a centrally-directed multidisciplinary and modern facility, founded in 1995.

MS is caused by white blood cells that attack the central nervous system and cause the body to gradually deteriorate, often to a crippling extent. The Sheba researchers have been taking blood from patients in early stages of the disease, multiplying the cells that attack the nervous and put them through a special process that causes them to become inactive. The cells are then injected into the patients' bodies in large quantities, causing the immune system in the body to destroy them and triggering it in the future to destroy similar cells if they are created.

Forty-seven patients have participated in the vaccine trial thus far, with some of them receiving the real vaccine and others receiving a placebo. Though doctors who are conducting the trials do not know which patients are receiving which treatment, the relative reduction in attacks in the group overall has led them to be optimistic that when the double-blind barrier is removed, that the success of the vaccine will be impressive.

According to Achiron, "our goal is to vaccinate patients at the beginning of their disease hoping to prevent the advance of the disease and the crippling condition that can result."

Cohen is cautious about drawing conclusions and raising false hopes. "Only when we discover who among the patients is getting the vaccine and who is getting the placebo will we be able to access absolutely the precise influence of the vaccine."

**To ease another's burden,
help carry it.**