MID-AMERICA MYOSITIS KIT

Welcome to another edition of your KIT newsletter

Statins and Muscle Damage: The Real Cost

The Heart Protection Study Collective Group cost effectiveness findings published on 10 Nov 2006 in the British Medical Journal grossly misrepresented the costs of statin treatment in terms of myopathic consequences.

From the beginning of statin use the drug company prediction of likelihood of muscle problems has been grossly optimistic. Instead of the two per cent figure originally promised, the true incidence of muscle problems proves to be much closer to 20% and even than may be an underestimate according to Draeger's group.

In the Journal of Pathology 210: 94-102, 2006, Draeger A and others of the University of Bern, Switzerland reported that statin therapy induces ultrastructural damage in skeletal muscle in almost every patient and often without myalgia. Draeger's group did skeletal muscle biopsies from statin treated and non-statin treated patients and examined them using electron microscopy and biochemical approaches.

They reported clear evidence of skeletal muscle damage in statin treated patients despite their being asymptomatic.

Although the degree of overall damage was minimal, it was the characteristic pattern of damage, including rupture of critical structures that caught the attention of the investigators. These findings support the hypothesis that statin induced cholesterol lowering per se contributes to myocyte damage and suggests further that it is the specific lipid / protein organs of the skeletal muscle itself that renders it particularly vulnerable.

Another previously unsuspected mechanism for muscle damage is selenium inhibition. Mooseman and Behl postulate that this type of myopathy is due to direct interference of the isopentyl step of the mevalonate pathway as a consequence of the almost inevitable statin induced fall in available selenoproteins. The substrate for this reaction, isopentanyl pyrophosphate IPP, is a direct metabolite of mevalonate.

All statins inhibit this function. The resulting clinical picture of statin associated myopathy includes a non-uniform pattern of muscle aches and pains, weakness and tenderness with easy fatigability. It can vary from mild to very severe, or even be disabling. This pattern of signs and symptoms is very similar clinically and pathologically to those induced by severe selenium (selenoprotein) deficiency, supporting their hypothesis.

An additional factor is that some patients may have a genetic susceptibility to statin use. Special genetic susceptibility may explain not only much of our statin associated rhabdomyolysis but also the curious pattern of persistent myopathy, often following only a short course of statins. Since susceptibility testing of this type is not yet available, there is no way to identify these susceptibles until the damage is done.

One of these genetic determined enzymatic conditions is carnitine palmitoyl transferase (CPT) deficiency. The enzymes involved are found on different membranes of our mitochondria, those busy factories within each of our cells responsible for the production of our (ATP) energy. Produced in each of our body's million's of cells, mitochondrial ATP is our body's sole source of energy. CPT enzymes work together with Coenzyme Q10 in the process of transport of fatty acids into our mitochondria and their ultimate conversion into fuel. Deficiency of this class of enzymes is characterized by unusual muscle pain and stiffness after exercise or work.

Campbell recently has described five cases of **polymyositis** due to statin drugs, which appear to be due to causes different from the usual, more common types of muscle damage. Cortisone

therapy was required in all five cases raising the possibility of statin pro-inflammatory effects in some people. Campbell proposes a previously unsuspected effect of statins on our muscle cell lipid / protein "rafts", recently described, that results in a tendency to apoptosis (cell death and disintegration). It is these remnants of apoptosis that incite the autoimmune reaction and cause the inflammatory response.

Chapman and Currie's work on the ubiquitin proteasome pathway (UPP) reveals a curious effect of exercise on several of the components of this pathway, offering yet another mechanism to explain some of the other statin induced myopathy.

Thus, five new mechanisms of statin damage to muscles have been reported just in the past two years and are added to my original hypothesis of the primary cause being statin induced CoQ10 deficiency with loss of cell wall integrity. Two of these (cholesterol lowering per se and selenoprotein inhibition) involve mechanisms that seem to be "across the board" and one (genetic susceptibility) involves a process that cannot be identified ahead of time without special testing.

Such observations strongly argue against excessively liberal statin use and especially over the counter distribution of such drugs. It is one thing when a drug causes a few aches and pains and something entirely different when the aches and pains may be permanent and disabling or, as in rhabdomyolysis, even fatal.

Dr. Beatrice Golomb of the NIH funded UCSD statin study reports a myopathy rate among her thousands of case reports as close to 40% a figure very close to that of my own statin side effect repository with its several thousand case reports.

The people who made this cost effectiveness study have not done their homework. Cost means far more than money when used in these determinations. If, on the other hand, the authors intended it to be just money, then their assessment is worthless.

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Sun Exposure May Trigger Certain Autoimmune Diseases in Women

Ultraviolet (UV) radiation from sunlight may associated with the development of certain autoimmune diseases, particularly in women, according to a study by researchers at the National Institute of Environmental Health Sciences (NIEHS), part of the National Institutes of Health.

"This study found that women who lived in areas with higher levels of UV exposure when they developed an autoimmune muscle disease called myositis were more likely to develop the form known as dermatomyositis, which weakens the muscles and causes distinctive rashes, instead of the form called polymyositis that does not have a rash," said Frederick W. Miller, M.D., Ph.D., chief of the Environmental Autoimmunity Group, Program of Clinical Research, at NIEHS. "Although we have not shown a direct cause and effect link between UV exposure and this particular autoimmune disease, this study confirms the association between UV levels and the frequency of dermatomyositis that we found in a previous investigation," said Miller.

The study, published in the August issue of Arthritis & Rheumatism, is also the first to evaluate and find a possible UV radiation association in autoimmune diseases in women.

According to Miller, women are more likely than men to develop many autoimmune diseases, but the reasons for this have not been clear. "We only found the association between UV exposure and dermatomyositis in women and not in men, and it could be that inherent differences in how women and men respond to UV radiation may play a role in the development of certain autoimmune diseases," said Dr. Miller. Miller also noted that other researchers have shown that female mice develop more skin inflammation after UV light

exposure compared to male mice and these effects may be related to the new findings in dermatomyositis.

The study was designed to determine if there was a relationship between the level of UV exposure at the onset of the disease and the type of myositis and autoantibodies that people developed. Dermatomyositis and polymyositis are the two major forms of myositis and both are considered autoimmune diseases, in which the body's immune system attacks muscle or skin and sometimes other tissues. Dermatomyositis is typically accompanied by a distinctive reddish-purple rash on the upper eyelids or over the knuckles and is often made worse with sun exposure.

To conduct the study, the NIEHS researchers collaborated with myositis centers across the country that had seen 380 patients who had been diagnosed with dermatomyositis or polymyositis and determined their autoantibodies. "Patients with autoimmune diseases make a variety of autoantibodies that are unique to different conditions. One autoantibody specifically associated with dermatomyositis is called the anti-Mi-2 autoantibody and we know from our previous research that UV radiation increases levels of the Mi-2 protein that this autoantibody binds to," said Miller.

In addition to finding an association between the level of UV radiation and the proportion of women who developed dermatomyositis compared to polymyositis, the researchers found an association between UV levels and the proportion of women with the anti-Mi-2 autoantibody. "More research is clearly needed to understand the potential links between UV radiation and the development of autoimmune diseases and autoantibodies in women," said Miller.

"While the causes of autoimmune diseases are not known, we suspect from emerging research that they develop after one or more environmental exposures in genetically susceptible people," said NIEHS Director Linda Birnbaum, Ph.D. "This study adds UV radiation to the growing list of environmental

exposures possibly important in the development of autoimmune diseases."

The NIEHS supports research to understand the effects of the environment on human health and is part of NIH. For more information on environmental health topics, visit our Web site at http://www.niehs.nih.gov.

The National Institutes of Health (NIH) — *The Nation's Medical Research Agency* — includes 27 Institutes and Centers and is a component of the U.S. Department of Health and Human Services. It is the primary federal agency for conducting and supporting basic, clinical and translational medical research, and it investigates the causes, treatments, and cures for both common and rare diseases. For more information about NIH and its programs, visit www.nih.gov.

Reference: Love LA, Weinberg CR, McConnaughey DR, Oddis CV, Medsger TA, Reveille JD, Arnett FC, Targoff IN, Miller FW. "Ultraviolet Radiation Intensity Predicts the Relative Distribution of Dermatomyositis and Anti-Mi-2 Autoantibodies in Women." Arthritis & Rheumatism. August, 2009.

Make a Medical History Log

If you already haven't done so, start a medical history log dating back to as long as you can remember or can get records for. It's always good to carry a copy of this log along and give it to your medical professional that you want treatment from.

Your medical history should include not only your current medications, but as many past prescriptions as you can remember along with the dates that you started and ended taking those prescription.

Keep your log up-to-date and print off a new revised copy to give to your doctor at your every visit.

If you can make your medical history log on a computer, make sure to include any blood sample history by scanning copies for your electronic record.

Your medical history will come in handy not only in use with a new physician, but can also serve as an important

instrument when filing for disability, if that time ever comes.

Tentative Agenda 2013 Annual Patient Conference

There's still time to sign up to attend the National TMA Conference in Louisville! (Oct 17-20)

Topics to be covered:

Access to care

Alternative and complementary therapies

Assistive technology

Chinese Medicine

Coping skills

Coping with prednisone

Dealing with stress

Diet and nutrition

The future of gene therapy

Individual insurance counseling

Individualized disease management

Informal disease management sessions

Introduction to myositis

IVIG, Acthar, rituximab

Jo1 and other syndromes

Lung disease

Medication side effects

New myositis research

Overlap syndromes

Planning ahead

Skin care

Swallowing problems

Travel planning

Water and land-based exercise

Your rights as a patient

New this year:

Apps for independence

Building your caregiving team

Driving assessment and rehabilitation

New world of mobility

Record keeping the right way

Veterans' sessions

Unfortunately…..

My travel plans to attend this year's conference in Louisville was changed during a recent trip to Wisconsin. I (Jerry King) realized that my IBM condition was no longer suited for long trips and the burden it placed on my caregiver was enormous. So, while still in Wisconsin, I contacted TMA and requested a refund for my conference fees. I will have to depend on hearing about the conference from others that attend and also by tuning in from home to the live webcasts sent from the conference.

KS/OK Gift Basket

As previously announced, we are collecting items locally manufactured in Kansas & Oklahoma to offer in a raffle at the national conference. All proceeds will go to the research fund of TMA.

We have been fortunate to receive items from the following companies so far:

Imaginary Designs – Newton, KS
Land of Oz Meats- Salina, KS
Bainter Sunflower Oil- Hoxie, KS
Bradley's Bones- Wichita, KS
Freddies- Wichita, KS
Best Darn Salsa- Newton, KS
Grace Hill Winery- Whitewater, KS

As previously requested, we need your help securing donations from your area.

Please contact Jerry King for the address where these donations can be shipped to.

Please patronize these sponsors with your future purchases.

A complete list of donors will be published at the end of the donation drive.

Keep Hydrated

Save These Dates

Next Mid-America KIT Meeting

Please plan on attending our next KIT meeting set for 1:00 PM, Saturday October 26, 2013 at the Civitan Community Center. Wichita, KS. Please respond to the email 'E-vite' you will receive about 10 days before the meeting date. A guest speaker is being planned.

TMA National Conference

The next TMA National Conference will be held October 17-20, 2013 in Louisville, KY.

Need a Scooter or Powerchair?

If you are planning to purchase a scooter or powerchair or require a patient lift or entry ramp on your own and won't be utilizing Medicare to assist in the purchase, there are many alternative approaches available these days. You may still be able to make a claim with your insurance after the purchase.

One company located in the New York area tends to the needs of individuals looking for a source other than your very expensive medical supply store where high prices make it almost impossible to afford a life changing option for coping with myositis. The company's name is Wizmall and their products can be found online. Mr. David Rhodes, President & CEO of Wizmall will help you select a product for your needs.

You can research his offering by going online at: http://stores.ebay.com/wizmall/

After you have researched the products, give David Rhodes a call at 212-596-7064. Ask for an additional 5% off the advertised price by mentioning your KIT Leader's name, "Jerry King" and tell him you are a member of the "Mid-America Myositis Support Group." If you order direct and pay by credit card rather than using Ebay or Paypal, he 'may' be able to save you some additional money.

Most of Wizmall's prices include free shipping to your doorstep.

Wizmall is a sponsor of your Mid-America Myositis KIT!

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Mid-America Myositis Kit
(Keep-In-Touch)
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