

Mark Your Calendars

The Virginia *Keep In Touch* support group meets quarterly. Make plans to come to the next meeting to hear from Ellen Montgomery, a physical therapist who works with several myositis clients, and to meet with other Virginia KIT members and their families.

When: Saturday, April 22, 2006
1:30 – 3:30 pm

Where: University Hospital
Conference Room A
1234 State Street

[From I-1, take Exit 2. Right on State Street. University Hospital is one mile on the left.]

If you plan to attend or have any questions, please contact John Doe at jdoe@myositis.org or 234-567-8901.



Future Meeting Dates

Plan ahead to join us at as many of these 2006 meetings as you can:

June 24
September 16
December 9

We look forward to seeing you!

Highlights from the Winter KIT Meeting: Dr. Smith speaks on trends in research

Dr. Smith, a specialist at the University of the East, addressed the Virginia *Keep In Touch* group members last month at the University hospital. He spoke about ongoing research as well as upcoming clinical trials.

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News and Notes from Our Members

Welcome Two New Members

Two new members have joined our group in the past three months:

George Smith lives in Smith, Virginia, with his wife, Joan. They have two grown children. George has PM, diagnosed this past summer. He enjoys reading and playing with his two grandchildren, 3-year-old Jack and 1-year-old John. He welcomes anyone to contact him at george@smith.com or 703-123-4567.

Martha Jones lives in Jones, Virginia, with husband John and two sons. Martha is 43 years old and was recently diagnosed with DM. She is an avid gardener and also loves to paint. Martha would love to speak to others with myositis: martha@jones.com or 540-123-4567.

Welcome to George, Martha and their families. We hope to see you and many other new members at our future meetings!

Send Us Your Ideas

Do you have something you'd like to see included in the *Virginia KIT Connection*? Feel free to email or call John Doe with your thoughts and ideas.

Your Messages



I have had severe PM for 13 years and feel that I can benefit both physically and mentally from aquatherapy. Does anyone have any recommendations for me? – Yvonneh/PM

I have done aquatic exercise for eight years and highly recommend it. I firmly believe it has kept me mobile. – Dorris/IBM

If you find that the insurance won't cover it, I would recommend checking out your local YMCA. I found a great conditioning class at my Y, plus I qualified for an extremely reduced membership rate. As far as I know, most YMCAs have financial aid programs. – Kristin/DM

I started yoga four years ago and continue to do it 2-3 times a week. I am in remission (so that helps), but I think it has done me a world of good, both mentally and physically. I started because the yoga was almost exactly the same exercises as my physical therapist was recommending. If you have a good yoga teacher you will stretch almost every muscle in your body. A good

yoga teacher will also help you modify every position so that you can do yoga even if you are in miserable shape. I recommend yoga, but I would make sure you have a good teacher and start in a beginners' class. – Tom/IBM

I do yoga almost daily and, like some of the others, find it helps me emotionally as well as physically. I too am in remission but started when I wasn't. The increased flexibility and balance were huge for me! – Pastor Deb/DM

I'm so glad you mentioned the yoga from our conference (in Las Vegas) because that was something any of us could do. It's not traditional on-the-floor yoga, which made it much easier. If I'm correct everything was done right in your chair! I still do some of the stretches she taught us. They are amazing. I still have problems with the floor exercise; getting up and down after all that stretching was very hard. Maybe time and practice would make a difference. I guess I'm just so satisfied with my water workouts that nothing can compare anymore. My suggestion is to take your time and find what works best for you. – Kristin/DM

What's Happening at TMA?

Annual Conference

TMA's 2006 Annual Conference will focus on health and fitness, and will help you find the tools you need to help maintain physical and emotional well-being as you battle myositis. We're planning a highly interactive conference program focusing on maintaining your strength and fitness through exercise, nutrition, physical therapy and proper medical care. The expert Medical Panel will answer your questions about the disease, treatments and research.

2006 is an exciting year for myositis research. For the first time, two multi-center drug trials related to myositis treatments are recruiting patients. One of the high points of the Conference will be reports from the researchers involved in these trials. TMA's Medical Advisors will present in the Expert Medical Panel session on new developments related to finding the cause and, eventually, a cure for myositis. Breakout sessions will show you ways to help control your disease through multiple therapies and preventive measures.

Whether you are newly diagnosed or very experienced with myositis; whether you are a family with a child that has juvenile myositis; or whether

you are a caregiver for an adult who has IBM, PM or DM, you will find the Conference educational, enriching and rewarding.

The conference will be held at the Hilton at Disney World Resort in Orlando, Florida. Take advantage of the long Labor Day weekend and enjoy the comfort and magnificent setting of one of Orlando's premier resort facilities. The lavish Hilton, with its impeccable service, is available to TMA conference attendees for the very reasonable rate of \$115 per night for a double room or \$155 for a junior suite.

To accommodate your special needs and maximize your comfort, the Hilton Resort offers 47 ADA rooms and more roll-in showers than at any other TMA Annual Conference hotel ever. They have also acquired bed-risers and toilet high-hats which will be available by special request, and on a first come, first serve basis. Please be sure to let the operator know about any special needs when reserving your room.

The Chairman's Campaign

My name is Ed Grass, and I am the Chairman of the Board of The Myositis Association (TMA). I am writing to spread

the word about the group of diseases known as myositis, let people know about urgent efforts underway to find a cure, and suggest one easy way for TMA members, family, and friends to assist.

Who we are

I was a former athlete and otherwise quite healthy until diagnosed at the age of 30 with a serious illness known as Myositis—or "bend-over" disease, as my young kids now call it. Myositis is a degenerative disease, which causes the body's own immune system to attack and kill muscle. Myositis can lead to complete disability, including the inability to walk, stand, or even swallow.

Like many TMA members with my form of the disease, Polymyositis (PM), I have lost the ability to play sports, pick up my children, or get up from the floor or a chair. Unfortunately, there are other versions of myositis besides PM, some of which can prove fatal.

Juvenile Dermatomyositis (JDMS) sometimes strikes children as young as 2 years old. Kids with JDMS often get serious, sun-sensitive rashes that can prevent them from even playing outside. Many JDMS kids, some in Wheelchairs, require injections and unpleasant medication to try to get and keep their JDMS in remission.

Photos from Our Winter Meeting



Contact Us

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