

**Report from RICHMOND....**

*No, it's not some political diatribe, just the notes from our latest KIT meeting that was held in Richmond last month I apologize for the **delay** in getting the newsletter out)..*

Seventeen of us (9 members and 8 Spouses/Caregivers) gathered at St. Mary's Hospital in Richmond on October 14, 2009 for the periodic meeting of the Virginia, West Virginia and NE North Carolina (VA/WV/NCne ) Keep In Touch (KIT) group. Those attending included **Alouise** and Jim Ritter, **Bob** and Erma Sanders, **LaShan** Lanier-Davis (along with her mother and her nurse), **Bill** and Dot Humphrey, **Earl** and Gina Soles, **Sara** Jennings (and her mother Joan Burton), **Al** Gregory, **Anne** Durica and **Hugh** and Shelby Fillingane. The breakdown by disease of those present was IBMS 5, DM 2 and PM 2.

Something NEW this time was the CONFERENCE CALL. After a few hiccups (and some expert assistance by new member **Sara** Jennings, a nurse at St/ Mary's) we were able to get the call established. We were all very pleased to hear **Stephen** Chuta who joined us via telephone. Unfortunately, he was the only one who called-in successfully, although Alouise tells me Rosemary Finch had tried. Steve brought our total attendance to 20 counting his 2 caregivers.

**Anne Durica** led the meeting and provided an overview of the recent TMA Conference in Charlotte. She showed some photograph she had taken that gave the KIT attendees a feel for the place and the people attending. Others of us who had been there (Al Gregory, LaShan Davis-Lanier, and Shelby and me) also shared our impressions, all of which were very favorable. We had some lively and informative discussions as described in the boxes below.

**Brief summary of comments from around the meeting room:**

**Al** Gregory (AG): the V.A. custom-makes wheel chairs. He decided a wheelchair was better than a scooter for him after several falls on the scooter. (I wonder if Al was trying to do "wheelies".)

**Bill** Humphrey (BH): emphasized that a wheelchair needs tilt, recline and elevation capability; get one for 5 years down the road; get a prescription from your doctor.

**Steve** Chuhta (SC): his son made a ceiling lift for him...worked well..."Jazzy" he said. He also has a hook-to-arm device that allows him to feed himself.

**Hugh** Fillingane: noted that van conversion vendors at the TMA Conference emphasized that used converted vans were scarce; so keep your eyes open for potential availability if you may be needing one.

**BH:** Van conversions cost about \$45k to \$65k. MTI in Waynesboro has new and used ones.

**AG:** V.A. in Richmond is excellent!! Top notch equipment.

**LaShan Davis-Lanier** (LD): gave her very interesting story about her "*Mystery Diagnosis*" (a Discovery Channel video; now available on YouTube)...with her multiple diseases...many different meds...Wow!!!

**SC and Edie:** thought the conference call was an excellent idea.

# VA/WV/NCne KIT Newsletter - November 2009

## WELCOME to our NEW Members

**Sara Jennings** (DM- 2009) – Dewitt VA

*Sara is a forensics nurse at St. Mary's Hospital. She tells me a "forensics" nurse is one who treats patients whose illness or injury may result in some legal proceeding (correct that if I'm wrong Sara!).*

**Kimberly Ann Spurlock** (DM-2009) – Charleston WV

*Kim is a physician (GP), recently diagnosed with DM..*

## Some of the comments heard at the meeting about the 2009 TMA Conference in Charlotte:

- **"Mis-diagnosis"** was **heard repeatedly** in the personal stories from various TMA members  
There was a lot of talk (among patients) about some association of myositis and **statins**; but no definite proof of linkage was provided by either doctors or patients
- Good presentations on **exercise and physical therapy** by a very enthusiastic group of PT'ers from a local university
- Excellent presentations from the doctors on the **Medical Panel**. Some intriguing stuff but nothing right away.
- Excellent opportunity to share methods of **coping with the disease** and to see the **mobility assistance devices** other people are using and to hear first-hand about their effectiveness, caveats, advice and just general information. Methods of coping and adapting.
- Lots of very Interesting and specific information during the presentations and discussions (see list on next page).
- Well Organized by TMA

**General:** everyone in high spirits...helps foster good attitudes...realization that the disease is different for each person...good info to help plan for your future...the food excellent...rooms were nice but doors were heavy...BH says doors can be adjusted, call maintenance...the extra charges of \$18 / day/for parking and \$9/day for Internet drove the room costs up significantly (internet access is usually free)...maybe a suburban venue would be less expensive...non-handicapped rooms were small for wheelchairs...some of the conference rooms were too small for the crowds that showed up for some sessions...Bob Goldman provided an excellent explanation of TMA's relationship with MDA...there were some very good comments among conferees about MDA services ...LaShan thought the agenda was a bit crowded. I tended to agree but then we seemed to come to the conclusion that was unavoidable, given the breadth of the conference and the time constraint...in summary, an EXCELLENT conference!!!

## List of topics from the THA Conference Agenda

(Presentation material for all these subjects is available on the TMA website at [www.myositis.org](http://www.myositis.org))

- Conserve your energy with devices and modifications
- What to expect from a clinical trial
- Caregivers cope with stress
- Social networking offers support
- Myositis for beginners
- Fall prevention and recovery
- Emotional aspects of chronic diseases
- Practical strategies for caregivers
- Autoimmune disease, Diet and Stress
- Understanding medications, pain control
- Spiritual, emotional and physical intimacy; how to preserve it despite your disease
- IVIG: How it works and why it can help some
- Techniques for driving with physical limitations
- Managing your disease (specific sessions for DM, PM, IBM)
- Acupuncture and Chinese medicine
- Current myositis trials, what's ahead
- Gene therapy for myositis
- How research in other diseases advances understanding of myositis treatment
- Environmental factors – (including statins)
- Coordinating your care between health professionals
- Exercises for every level
- One size doesn't fit all: finding your unique nutritional needs
- Myositis and cancer
- Introduction to aquatherapy

*The Myositis Association website is a most valuable resource for all types of information on the various diseases including clinical trials, new research, webcasts and much more. Take a peek!!!*

[www.myositis.org](http://www.myositis.org)

## VA/WV/NCne KIT Newsletter - November 2009

### MEETINGS

We have met in Richmond in the recent past, but there is precedent for holding the meeting elsewhere if warranted. We had about 30% attendance by KIT members last week and that seems to be relatively consistent.

I did a quick analysis of where our members live and came to the conclusion that most (16) live within about 1.5 hours of Richmond (That includes those living in Charlottesville, Fredericksburg, Williamsburg and East of Richmond). Eight are just as close to Harrisonburg (to include those living in Charlottesville and west of there). However, few if any of those to the west attend the meetings in Richmond.

So, that leads to the question: Would more or different members come to a KIT meeting if it was held in Harrisonburg or Charlottesville? **I would like to hear from you on this subject.** So please contact me (see contact info below).

Anyway, our **next meeting** is tentatively scheduled for sometime in **March 2010** in **Richmond** depending on what date **Bob** can schedule a meeting room at St. Mary's. So stay tuned...and **THANKS Bob.**

*Please send comments or questions you have for the KIT group and I will send them around.*

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*Bob and Alma Sanders – Meeting Facilitators (804-270-1765)*

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*The opinions expressed in this newsletter are not necessarily those of The Myositis Association or the VA/WV/NCne KIT support group. We do not endorse any product or treatment we report. It is our intent to keep you informed. We ask that you always check any treatment with your physician.*