



Mal de Debarquement Support News
A Newsletter for the International Members
of the MDDS Support Group
and the Professionals Who Treat Them

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MdDS Research Sails Forward at UCLA

One of the many challenges to understanding the neurological basis of Mal de Debarquement is that there is very little hard scientific evidence that explains the persistent sense of movement that MdDS patients experience. Moreover, most literature on MdDS has been centered on case reports through which it is difficult to understand the spectrum of the disorder. Our recently completed retrospective review and questionnaire study on patients diagnosed with MdDS at UCLA revealed some interesting new features of the disorder that are now the basis of our continuing research studies. (These results have been accepted for publication in the *Journal of Neurology*.)

There were three novel features of MdDS noted in our research. One was that patients who developed recurrent episodes of MdDS tended to have longer and longer attacks. Second, a sizeable proportion of patients with classical motion triggered MdDS (such as after a cruise) developed spontaneous episodes of MdDS after the first episode had resolved. This indicated that there is some kind of memory for the environment that originally lead to MdDS and that this can either be strengthened by a subsequent exposure or could reactivate even spontaneously. This would be akin to being able to play a very well rehearsed piece on an instrument years after never having played it—there is a persistent unconscious motor memory over learned events.

Finally, we noted that a large proportion of patients developed sensitivity to visual motion with the onset of MdDS. For those with recurrent events, the visual motion sensitivity coincided with the MdDS only. This was manifested by feelings of nausea and disorientation when exposed to rapid or repetitive visual stimuli such as freeway traffic, action movies, alternating patterns of any kind, or even something as simple as hand gestures.

Since the visual system works in tight conjunction with the vestibular system, our current research efforts are focused on quantifying problems in visual motion processing. The initial phase involves undergoing a 1-hour computer-generated visual perceptual task administered on a computer. This test is designed to determine how well patients can detect visual motion of different speeds, as well as visual motion in a background of random motion. MdDS patients will be compared to patients who have absent vestibular function (either medication induced or sporadic) and to those whose primary problem is in visual motion sensitivity in the absence of a history of MdDS.

The second phase of the project will involve a roughly 30 minute functional MRI scan of the brain. Functional MRI scans determine where the brain uses oxygen during particular tasks and

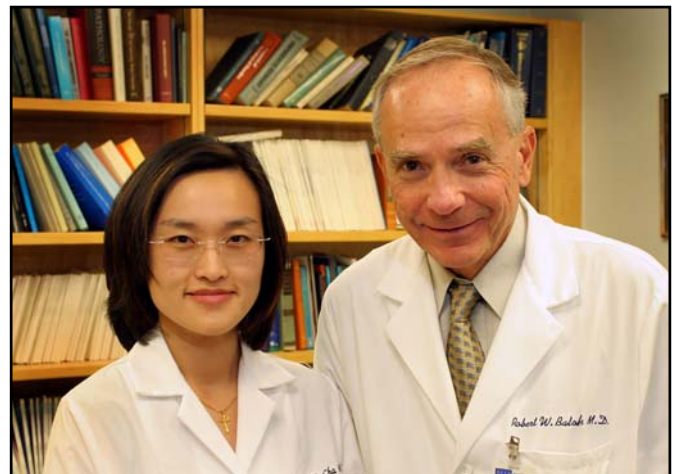
are very helpful in localizing the function of different parts of the brain. In our study, the participants will be shown different kinds of visual motion stimuli and the pattern of brain oxygen usage will be determined.

Most areas of the brain that process information on balance (vestibular) also process visual information. Therefore, changes in these areas to visual motion stimulation can give us a good idea of how the balance in vestibular and visual processing are affected in MdDS patients. Once we have a better understanding of how information relevant to postural control is processed at the cortical level, we will be in a better position to design treatment that has a good theoretical basis for success.

All good clinical research requires the collaboration of people of diverse skills. Our current research involves specialists in neurology, movement disorders, imaging, and psychology. Partnership with patients is also a critical aspect of this as scientists learn to ask the relevant questions from patients and patients are the ultimate beneficiaries of the research.

The support from the MdDS Balance Disorder Foundation through the *Early Career Distinguished Investigator Award* came at a critical time in the study. As there are no separate research funds for MdDS study at UCLA currently, this support has been crucial in recruiting subjects for the pilot phase of the study. We are hopeful that this will lead to longer term funding. I am very grateful to the Foundation and to the patients and donors who have made this Award possible and am hopeful that it will be the springboard to long-term research on MdDS at UCLA.

Yoon-Hee Cha, MD



Yoon-Hee Cha, MD, and her mentor, Robert Baloh, MD from the Department of Neurology at UCLA. Dr. Cha received the *Early Career Distinguished Investigator Award* from the MdDS Balance Disorder Foundation. Photo by Reed Hutchinson.

Souvenir from Working on a Cruise Ship I am a 24-year-old male who has been rocking and swaying for almost 2 years. My symptoms began while I worked and lived on a cruise ship from April of 2006 to July of 2008. Prior to embarkation, I was sent to a training school in Piney Point, Maryland for a month where I got a very bad cold with sinus and ear pressure (not sure if this is associated). The first month went great! I was feeling better and living the dream! Then the hours started to pick up. I was working close to 80 hours a week. I began to lose sleep and my stress level increased. I then started to notice that every time I left the ship I would sway as if I were still on it. At first, I thought nothing of it and went on working thinking it would pass. One and half months went by and it was getting worse. I could not even leave the ship without having a panic attack. Finally, I gathered the courage to book a flight back home to Denver in July. Here I am today still dealing with it. I have been to numerous doctors and no one has any idea what is wrong. I have found that the more I fight the motion the more anxiety comes and this makes more motion. Therefore, what I am trying to do is make friends with the motion and enjoy its company. This way I can slowly retrain my balance without the cloud of anxiety. I am praying with all my heart that we all eventually find some solid ground! God bless! Chris

What works? What doesn't? Pharmacotherapy for MdDS

The MdDS Balance Disorder Foundation has continued efforts to solicit information from those affected with MdDS. Using an electronic survey at our public website (www.mddsfoundation.org), respondents reported their *responses to various medications commonly prescribed in the treatment of MdDS*. Of 112 respondents, 92 had been diagnosed with MdDS by a medical professional; 90% of these diagnosed individuals had developed MdDS following a motion event. The following summarizes some of the findings only from those diagnosed with MdDS (complete results are provided at www.mddsfoundation.org/MdDS_survey.html).

Drug	Number Treated	Improved (% of subjects receiving this treatment)	Worsened	Unchanged
Meclizine (antivert)	58	9	10	81
Klonopin (clonazepam)	50	82	10	8
Valium (diazepam)	44	48	11	41
Amtriptyline (elavil)	27	29	19	52
Ativan (lorazepam)	26	50	19	31
Scopolamine patch	25	12	28	60
Nasonex	16	19	0	81
Neurontin (gabopentin)	14	21	21	58
Betahistine (serc)	13	15	0	85

Although over 60% of subjects with MdDS received meclizine (antivert), few were benefited by this therapy. In contrast, other widely prescribed drugs (klonopin, ativan, and valium) were of benefit to many patients. It remains to be determined if there were sustained beneficial effects or contraindications for these drugs and/or if the use of these drugs at the time of diagnosis would have changed the duration of MdDS. Carefully controlled, clinical research studies are required to establish the optimal pharmacological approach to the treatment of MdDS.

Your Contributions Count!

Operating as a 501(c)(3) nonprofit organization, your tax exempt donations to the MdDS Balance Disorder Foundation in support of research and educational and advocacy programs are encouraged.

We are now able to accept contributions using Pay Pal and credit cards.

Visit www.MdDSfoundation.org or use the donate button below.



Or please send checks to:

MdDS Balance Disorder Foundation
Marilyn Josselyn, Treasurer
255 Copper Beech Drive
Blue Bell, PA 19422

If you are interested in volunteering to assist with our programs, please email:

Sharon: lodilawyer@yahoo.com

Needed: assistance with entry of data into a MS Excel spreadsheet to help the Foundation achieve current goals

For further information about the Foundation or to learn more about MdDS, please visit our website at www.MdDSfoundation.org

Send comments, questions, or suggestions to the [Newsletter Editor](#).