



# Multiple Sclerosis Quality of Life Project

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## AUTUMN 2011 RESOURCES

- Meet the new Newsletter Editor
- Resources for living well with MS
- A source for free audiobooks
- An interview with our Clinical Manager
- Review of Dr. Shaffer's presentation
- Support Groups
- Upcoming events
- MSQLP Calendar
- In Memoriam

## TOPICS of PAST ISSUES

- Nourishment: November 2007
- Caregiving: February 2008
- Anxiety: May 2008
- Advocacy: August 2008
- Mobility: November 2008
- Housing: February 2009
- Bowel Management: May 2009
- Wellness: August 2009
- Celebrate 10 Years: June 2010
- Changes at MSQLP: Autumn 2010
- Finances: Winter 2011
- Communication: Summer 2011


To read previous issues, go to [www.msqlip.org/learn/newsletter.html](http://www.msqlip.org/learn/newsletter.html)

## Letter from the Editor

—Amy Lamb Heckel, RDH

Yes, yet another change here at MSQLP. As most of you already know our beloved newsletter editor, Donna Krasnow, has moved out of state. Now I have the unenviable task of trying to do as well as she has. Thank goodness I have the formidable technical and editorial skills of Mary Wessling MS PhD (also our Vice President) to help me.

Good news! As the title of Mary Wessling's article reminds us, resources abound for those living with MS. Our goal is to help you locate and utilize those resources. Some of these resources may already be familiar to you, some may be new. Take a look. One of my personal favorites is the National Library Service, which provides audio books cost-free to persons who qualify (this is not income based).

As a MSer myself, I know just how difficult life with MS can be. The Merriam-Webster dictionary defines resourcefulness as an ability to meet and handle a situation. It is our hope that you will be able to discover within these pages some sources of support that will enable you to become even better equipped to handle the situation of life with MS. 

## Resources abound for living with MS!

—Mary Wessling, PhD

### MSQLP as a resource

Over its 11 years of existence, our organization has evolved into a powerful resource for persons with multiple sclerosis, their families, and caregivers—and of course, the last two are often one and the same. We'd like to continue our work by giving you leads to resources in books and online that will extend our services in the way that you as an individual find most helpful.

New among our services is the Borrowing Book Library that will be in full operation in September. Books will range from those of interest mainly to the newly diagnosed or MS veterans. The topics cover coping with, living with, and moving on with MS; research on MS, and life experiences with MS and the healthcare program.

TOTAL NUMBER OF  
CLIENTS WITH MS

- Aug-Dec 2004: 21
- 2005: 59
- 2006: 119
- 2007: 173
- 2008: 201
- 2009: 226
- 2010: 248

## Books

I'd like to start by mentioning a few books that I have found very interesting, and you might find useful.

For example, to prepare for one topic that we've covered extensively in previous newsletters, I relied heavily both on our in-house experts and a slim paperback ***What to Ask the Doc: The Questions***

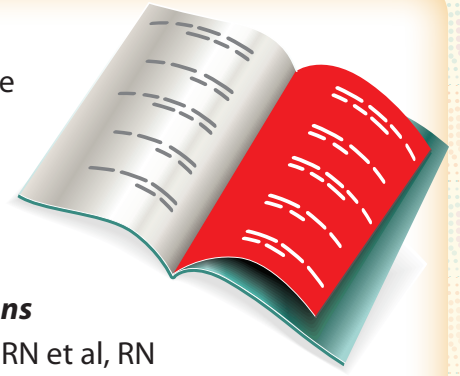
***to Ask to Get the Answers You Need*** (M Fitzpatrick RN et al, RN Interactive, Inc., 2003). This book was assembled by a team of nurses and has a list of questions for many health problems. The pages on MS (108-109) provide a succinct list that you might abstract for your own use.

Michael Roizen MD and Metmet Oz MD take a more comprehensive approach in ***You the Smart Patient: An Insider's Handbook on Getting the Best Treatment*** (Free Press, 2006). Illness is no fun, to be sure, but somehow these authors have found the right level of seriousness, adding some typographic and pictorial touches to lighten up the otherwise very weighty subject. Their pages on alternative medicine are especially good.

Speaking of alternative medicine, Dr. Allen Bowling's ***Complementary and Alternative Medicine and Multiple Sclerosis*** (2nd Edition, Demos Medical Publishing, 2007) is the most comprehensive treatment of the topic. His final chapter, A Five-Step Approach: Integrating Conventional and Unconventional Medicine, both provides an action plan and succinct advice on the scientific and clinical merit of alternative medicine (which he refers to rather as "unconventional medicine."

Changes in cognition can be one of the most frustrating aspects of multiple sclerosis, both for the MSer and the caregiver. An excellent book for understanding cognitive changes is ***Multiple Sclerosis: Understanding Cognitive Challenges*** (LaRocca N and Kalb R, Demos, 2006). Each chapter focuses on a different aspect of cognitive challenge, and is written in language clearly accessible to most readers.

Finally, if you're tempted either by the media or just through your own interest to explore the medical literature about MS, there's a book in the MSQLP library that will help you interpret the statistics. What on earth is an odds ratio? How does a risk ratio apply to your situation? Be sure to read ***Know Your Chances: Understanding Health Statistics*** (Woloshin S, Schwartz LM, Welch HG. University of California Press, 2008). The subtitle of the book is "How to see through the hype in medical news, ads, and public service announcements." A fair warning: all new



TOTAL NUMBER OF  
CAREGIVER CLIENTS

- Aug-Dec 2004: 1
- 2005: 21
- 2006: 47
- 2007: 75
- 2008: 92
- 2009: 107

treatments take time to assess, and once approved, may be efficacious only for certain forms of MS.

There are many other useful books in the Borrowing Book Library. We will have a database of the titles available soon on the Web site, along with the rules that will ensure that everyone will have a fair chance to read the book that interests them.

### Internet

It's no secret that some of the information available on Internet sites is valuable, and some is not, or is even incorrect. The Woloshin book that I've mentioned previously will help you to evaluate what you see online. However, if even using a computer is difficult for you because of movement or vision challenges, you need another kind of information.



Fortunately, accessibility options abound for both Windows and Mac users. Here's a short list of sites with a lot of helpful information.

#### For the Mac:

- The most wide-ranging discussion of the range of accessibility is found at <http://www.apple.com/accessibility/>
- The page for assistive technologies for vision disabilities, with a link to third party solutions for the Lion operating system is <http://www.apple.com/accessibility/macosx/vision.html>
- The corresponding page for movement problems is <http://www.apple.com/accessibility/macosx/physical.html>

#### For Windows (newer versions):

- A site that offers a broad range of options, including links to accessibility options for Internet Explorer and Microsoft Office (newest versions only) <http://www.microsoft.com/enable/>
- Microsoft's Ease of Access Center offers general information about the range of accessibility features available for Windows at <http://windows.microsoft.com/en-us/windows7/What-accessibility-features-does-Windows-offer>

*We thank our volunteers!*

- Carieanna Hess
- Marie Swank
- Larry Swank
- Jane Brown
- Tammy Jennings
- Terry Bennett
- James Kern

### For previous versions of Windows:

- A Web page giving useful suggestions about accessibility options available for previous versions of Windows OS programs including Windows XP, Internet Explorer, and Firefox is <http://www.icommunicatetherapy.com/accessibility>
- And of course, the MSQLP Web site, which is designed for accessibility. Thanks to our previous intern Margot Frye and Board Member (and Editor of this Newsletter) Amy Lamb Heckel RDH, the set of pages at <http://www.msqlp.org/resources/index.html> is dedicated to resources of many different types. You can also access this set of pages by clicking on RESOURCES in the left hand navigation bar on the Home page, <http://www.msqlp.org>.

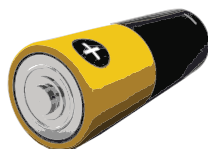
This concludes my list, but do read the next article for another fantastic, freely available resource. And, if you have additional suggestions for resources, please contact us! 🗨️

### Borrow audio books—for free!

—Amy Lamb Heckel RDH

“That All May Read” is the motto of the **National Library Service for the Blind and Physically Handicapped** (NLS.) You may be eligible to borrow audio books from them for free. “Talking Books” is a free (yes, really free) service that certain U.S. residents and citizens can sign up for. How does it work? The NLS website describes it this way: “local cooperating libraries throughout the United States mail NLS audio books, magazines, and audio equipment directly to enrollees at no cost.”

Does this sound too good to be true? My husband’s mother has been enrolled for years and has had nothing but positive experiences. She is especially thrilled that to return an item she only needs to put it in the enclosed postage-free envelope and then place it in her mailbox. On the next page is information from the NLS website defining who is eligible for their services.



## MSQLP's Seaside Support Group

- Oldemeyer Multi-Use Center  
986 Hilby Avenue,  
Seaside
- General and Caregiver Support group  
2nd Saturday of alternate months  
11am –1pm

## MSQLP's Salinas Support Group

- Salinas Valley Medical, Downing Resource Center
- General Support Group.  
3rd Friday of alternate months  
11am –1pm

### Do you qualify?

Here are the criteria:

- 1 Blind persons whose visual acuity, as determined by competent authority, is 20/200 or less in the better eye with correcting lenses, or whose widest diameter of visual field subtends an angular distance no greater than 20 degrees.
- 2 Other physically handicapped persons are eligible as follows:
  - Persons whose visual disability, with correction and regardless of optical measurement, is certified by competent authority as preventing the reading of standard printed material.
  - Persons certified by competent authority as unable to read or unable to use standard printed material as a result of physical limitations.
  - Persons certified by competent authority as having a reading disability resulting from organic dysfunction and of sufficient severity to prevent their reading printed material in a normal manner."

In cases of blindness, visual impairment, or physical limitations, "competent authority" is defined to include doctors of medicine; doctors of osteopathy; ophthalmologists; optometrists; registered nurses; therapists; and professional staff of hospitals, institutions, and public or private welfare agencies (e.g., social workers, case workers, counselors, rehabilitation teachers, and superintendents). In the absence of any of these, certification may be made by professional librarians or by any person whose competence under specific circumstances is acceptable to the Library of Congress.

In the case of reading disability from organic dysfunction, competent authority is defined as doctors of medicine and doctors of osteopathy who may consult with colleagues in associated disciplines.

The application for "Talking Books" can be found online at <https://www.nlstalkingbooks.org/talkingbooksform/>

You can also telephone **1-888-NLS-READ**.

This is a great program—another resource you might not have known about! 🚀

TOTAL NUMBER OF  
HOUSE VISITS

- Aug-Dec 2004: 57
- 2005: 286
- 2006: 346
- 2007: 715
- 2008: 993
- 2010: 1,292

## Disability.gov Update:

### The White House Wants Your Ideas

#### Topics to Be Discussed During Monthly Disability Calls

Each month, White House staff who work on disability-related policies host a public, live-captioned conference call to keep the public better informed about important developments on many different disability issues. These calls also connect you to leaders in the federal government who work on these issues. Over the past several months, monthly conference calls have featured discussions on accessibility, employment, education, technology, emergency preparedness, transportation, healthcare and the federal budget.

The White House is now offering the opportunity for you to suggest topics you'd like discussed during these calls. Send in your ideas about subjects for discussion, as well as the federal officials you'd like to hear from on these subjects, by visiting <http://tinyurl.com/3ctfyda>.

Visit Disability.gov for information about these and many other subjects:

- Finding employment
- Help finding and paying for housing
- Laws that protect your rights as a person with a disability
- Disability benefits
- Scholarships and other financial aid
- Federal government grants

Looking for organizations, programs or services near you? Visit Disability.gov's Information by State section.

Visit Disability.Blog to read and comment on a wide variety of subjects of interest to the disability community, including benefits, healthcare, housing and the special "Career Connections Series."

*Thanks to Gene Harter for this tip.* 🚀



PHONE CALLS WITH  
OR FOR CLIENTS

- Aug-Dec 2004: 480
- 2005: 5,246
- 2006: 11,414
- 2007: 15,823
- 2008: 19,493
- 2009: 22,373
- 2010: 26397



## Meet our Clinical Manager

Grant Helm earned a BA in Social Work from California State University Monterey Bay, and is now our Clinical Manager. It's a job that involves heavy and diverse demands. In those months while we were in the process of reorganizing the structure of MSQLP, Grant was key to keeping our focus on our clients, at the same time as he juggled the range of duties you will read about in this interview!

### **Q: What interested you in social work?**

The opportunity to serve my community. I believe, life isn't about the money you make, the car you drive, or the house you live in. It's about the people you meet, the virtues you learn, and the impact you make. I was first intrigued by social work when I learned about their involvement with veterans returning from the middle-east. It was clear to me that this profession is not about capitalizing on revenues, it was about establishing relationships and reaching out to those in need of assistance.

### **Q: What are your specific duties at MSQLP as Clinical Manager?**

As the clinical manager my duty is to manage and provide the resources and information available on topics such as medical equipment, insurance, disability, and financial assistance. I'm also in charge of house calls, client advocacy, office statistics, event promotions (media promotions, invitations to clients, calling clients), maintaining a client check-up schedule and up-keeping progress in helping complete each individual client's goals.

### **Q: That's a lot to do. How do you prioritize when you're short of time to fit it all into a single day?**

Clinically, I prioritize clients needs by the overall goal set for each client. For instance, if I am balancing six clients a day and one of these clients is in need of immediate housing because of impending eviction they will receive my main attention. I make sure to timeline every goal I set with a client so that we both can share a similar perspective on when to expect the deadline of completing a mutually set goal. Some clients don't need more than 15 minutes of time in my day for a specific resource, and typically, these clients will get the office's immediate action as well.

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### **Q: What are the most rewarding—and the most frustrating—aspects of your job?**

The most rewarding feature of working with MSQLP is making an impact on another individual's life everyday. Whether it's completing a goal, meeting/in-taking a new client, or catching up with a historic client, my favorite part of the job is the positive change that occurs when MSQLP establishes and ongoing relationship with a person with MS.

The most frustrating events occur when I have to refer a client to an agency outside of MSQLP for help that extends beyond our services. Because I know how hard it can be to find assistance especially when you are getting re-directed from organization to organization. If a situation like this occurs, I will do my best to find the appropriate agency that can provide the appropriate assistance. 🚀

### **William Shaffer MD—A Doctor with MS**

—Amy Lamb Heckel RDH

Wouldn't it be wonderful to have a neurologist who really understands multiple sclerosis? There is one out there. In fact, William Shaffer MD has MS himself. Dr. Shaffer's personal experience with MS has lead him to have a deep level both of both empathy with and understanding of everyday life with MS. He lives in Loveland, Colorado and works at the North Colorado Medical Center in Greeley, Colorado.

Dr. Shaffer gave a presentation on July 23 at the Embassy Suites in Seaside, which was cosponsored by EMD Sorono in cooperation with and MSQLP. He stressed the importance of each MS patient's having a good support system in place. He stated, "Family is most important." He substantiated that idea by speaking of his own relationship experiences, both positive and negative. He did remind the audience that the divorce rate among MSers is higher than the national average, yet encouraged us to utilize good communication and not be afraid to discuss important issues with our partners.

Dr. Shaffer discussed what many of us MSers describe as "heat intolerance." What is known to the medical community as "Uthoff's Phenomenon" or "Uthoff's Sign" was first described in medical literature by Wilhelm Uthoff in 1890. No, you are not going crazy, for many of you your MS symptoms worsen as your core body temperature rises. Several people in the audience found it validating to have a neurologist confirm that from personal experience. that the worsening of MS symptoms brought on by increased body temperature is temporary. Dr. Shaffer acknowledges that having an increase in symptoms can be very scary – temporary or not. This is what he had to say in Connection magazine, "Sometimes people are led to believe that working out makes their multiple sclerosis worse. When, in

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fact, the rise in body temperature may bring out the symptoms of MS, it does not cause attacks or exacerbations. Once the body cools down, the elevated symptoms should subside. When I was first diagnosed and I exercised, I would lose the feeling and control in my left arm and it scared me. Once my body cooled down, the feeling came back and I was fine. So it is easy to see that people with MS would draw the conclusion that working out is not good when in fact the opposite is true: it's important to stay active and eat healthy."

You can read about Dr. Shaffer in the Spring/Summer 2010 issue of Connection (the magazine of the Colorado Chapter of the National Multiple Sclerosis Society). His own website address is <http://doctorwithms.com/index.html>. Though his website is currently extremely limited, one can see by the address he has chosen that Dr. Shaffer is proud of what he can offer to the MS community. Dr. Shaffer formed a connection with the audience that few other speakers have achieved. If you have the opportunity to hear him speak, I recommend that you do so. *William Shaffer MD has approved this article.* 🚀

## Upcoming Events

**It's Walk 'n Roll time again**--our 5th annual walkathon around Lake El Estero will take place Saturday, September 24th, at Lake El Estero Park, Monterey.

This event has brought so much joy and fellowship to clients, caregivers, friends, and family since 2007. We set out together, circle the lake by foot or by wheel, arrive back at the starting point for music, entertainment, and a barbecue.

The event has as its focus increasing public awareness of multiple sclerosis, and especially recognition of the role MSQLP has played in the lives of persons with MS in Monterey, San Benito, and Santa Cruz Counties for more than a decade.

There's still time to join us, and if you're able, to support the event as a sponsor. Call (831) 333-9091, or send the interactive form on our Web site by email.

In addition to the familiar and annual Walk 'n Roll, we're doing a new and different first-time fundraising event: On October 8, we are sponsoring a performance of **Tom Parks' new play Paris is Paris is Gertrude Stein in Paris**. at the Carl Cherry Center for the Arts, Carmel. A cocktail supper will start at 5:30 pm; curtain time is 7 pm.

For information about obtaining tickets, call us at (831) 333-9091; for sponsor opportunities, call us, email us, or fill out the interactive form on our Web site.

A **teen workshop** for kids who have a parent or relative with MS will be held on a Saturday in early November: experiential activities, education, making connections, and fun. If you are interested or would like more information, please call Yesenia at (831)595-0505 or Andrea Dowdall (831)277-9121. 🚀

NEWS FROM OTHER ORGANIZATIONS

We'd like to hear from you if you know of activities that your fellow MSers would benefit from and enjoy.

## MSQLP CALENDAR



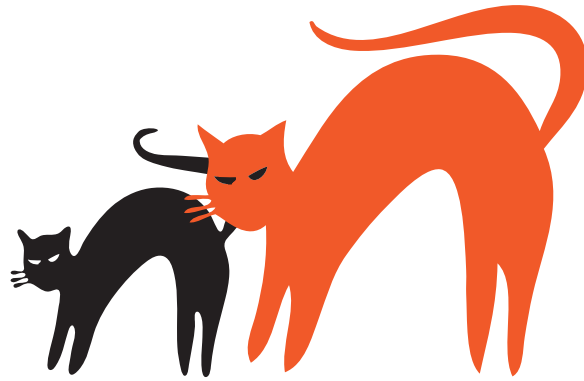
### September

- 5: Water Aerobics, Monterey Sports Center 12–1 pm**
- 7: Water Aerobics, Monterey Sports Center 12–1 pm**
- 8: Water Aerobics, Monterey Sports Center 12–1 pm**
- 10: Support Group, Oldemeyer Center, Seaside 11 am–1 pm**
- 12: Water Aerobics, Monterey Sports Center 12–1 pm**
- 14: Water Aerobics, Monterey Sports Center 12–1 pm**
- 21: Water Aerobics, Monterey Sports Center 12–1 pm**
- 22: Water Aerobics, Monterey Sports Center 12–1 pm**
- 24: WALK 'N ROLL**
- 26: Water Aerobics, Monterey Sports Center 12–1 pm**
- 28: Water Aerobics, Monterey Sports Center 12–1 pm**

### October

- 3: Water Aerobics, Monterey Sports Center 12–1 pm**
- 5: Water Aerobics, Monterey Sports Center 12–1 pm**
- 5: Water Aerobics, Monterey Sports Center 12–1 pm**
- 8: TOM PARKS' PLAY, Cherry Theater, Carmel**
- 10: Water Aerobics, Monterey Sports Center 12–1 pm**
- 12: Water Aerobics, Monterey Sports Center 12–1 pm**
- 17: Water Aerobics, Monterey Sports Center 12–1 pm**
- 19: Water Aerobics, Monterey Sports Center 12–1 pm**
- 21: Support Group, Salinas Valley Memorial Hospital, 11–1 pm**
- 24: Water Aerobics, Monterey Sports Center 12–1 pm**
- 26: Water Aerobics, Monterey Sports Center 12–1 pm**
- 31: Water Aerobics, Monterey Sports Center 12–1 pm**





## **November**

- 2: Water Aerobics, Monterey Sports Center 12–1 pm**
- 7: Water Aerobics, Monterey Sports Center 12–1 pm**
- 9: Water Aerobics, Monterey Sports Center 12–1 pm**
- 12: Support Group, Oldemeyer Center, Seaside 11 am–1 pm**
- 14: Water Aerobics, Monterey Sports Center 12–1 pm**
- 16: Water Aerobics, Monterey Sports Center 12–1 pm**
- 21: Water Aerobics, Monterey Sports Center 12–1 pm**
- 23: Water Aerobics, Monterey Sports Center 12–1 pm**
- 28: Water Aerobics, Monterey Sports Center 12–1 pm**
- 30: Water Aerobics, Monterey Sports Center 12–1 pm**

## **December**

- 5: Water Aerobics, Monterey Sports Center 12–1 pm**
- 7: Water Aerobics, Monterey Sports Center 12–1 pm**
- 12: Support Group, Salinas Valley Memorial Hospital 11 am–1 pm**
- 14: Water Aerobics, Monterey Sports Center 12–1 pm**
- 16: Water Aerobics, Monterey Sports Center 12–1 pm**

# In Memory Of...

**Kathy Phair**

