NARCOMS NOW

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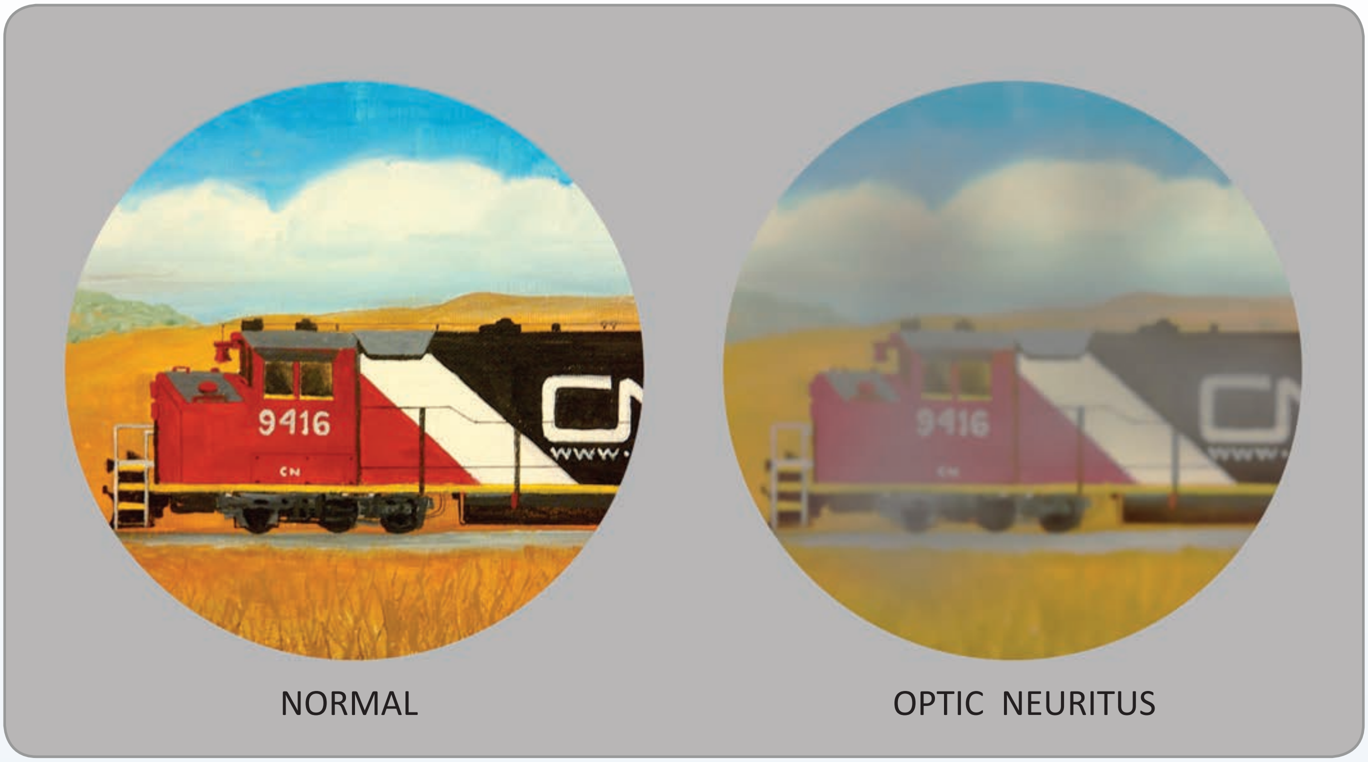
FOCUS ON VISION

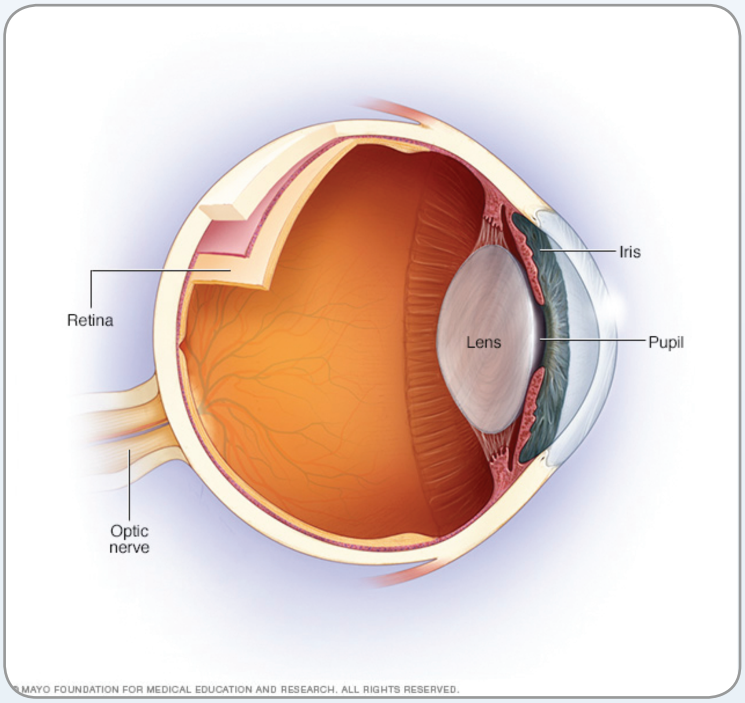
Representation of Visual Impairment

In keeping with the theme of this issue of *NARCOMS Now,* we thought it might offer some perspective to depict how a visual impairment can change one's vision. We used an original painting by Thomas "Jock" Murray, MD, renowned neurologist, and altered the image to depict how a common impairment in MS, optic neuritis, might affect how the patient sees. The original image is on left. The image on the right shows symptoms common with optic neuritis: lack of contrast, blurred vision, tonal color shifts.



NORMAL

OPTIC NEURITUS



Optic neuritis is an inflammation that damages the optic nerve, a bundle of nerve fibers that transmits visual information from your eye to your brain. Pain and temporary vision loss in one eye are common symptoms of optic neuritis.

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Winter 2017 Contents

NARCOMS NOW

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A Letter from the Director - *Winter 2017*

Greetings,

And just like that, we turn the page on another year and welcome 2017! It's hard to believe 2016 has come and gone—we wish you a very happy holiday season and a happy new year. It's also hard to believe we are coming up on five years of publishing *NARCOMS Now* magazine (in Spring 2017). We've come a long way, and we appreciate you joining us for the ride.

In this edition of *NARCOMS Now*, we are examining the impact of visual symptoms and conditions that can occur in multiple sclerosis. Visual symptoms are often the first signs that neurological changes are taking place, sending participants to see their doctors. We touch on some of the most common conditions affecting vision in individuals with multiple sclerosis, including optic neuritis, nystagmus, and displopia (see "Feature Focus," page 4.) In addition we review some of the more recent research in optical imaging as a tool to track disease progression in MS.

Dr. Ruth Ann Marrie is a Don Paty Career Scientist, practicing neurologist and Director of MS Clinic at University of Manitoba Health Sciences Center in Winnipeg, Canada.

You'll notice a change in the inside front cover page in this issue, where we modify the original artwork of renowned MS researcher and clinician Thomas "Jock" Murray (see our "Feature Focus" interview with him from Fall 2014) to reflect the impact of visual impairment that can be caused by MS. Tell us what you think!

"MS Reflections" is a closer look at research based on data provided by you, our NARCOMS participants, on tremor—a symptom many individuals with MS experience but which does not seem to have an effective treatment in many cases. In this issue of "MS Reflections" there is an exciting legislative announcement that will support medical research. "MS News" recaps the latest research news findings from the late fall European Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS) annual conference with a focus on research results in progressive MS.

As we head into spring, we thank you in advance for completing our Spring Survey. We are grateful for your continued participation in NARCOMS. Don't forget to send us your own MS stories for our "Faces of NARCOMS" feature in each issue.

Have a lovely holiday season and happy New Year!

Sincerely,

Ruth Ann Marrie

Dr. Ruth Ann Marrie
Scientific Director, NARCOMS

NARCOMS INFORMATION CORNER

Have an idea?

We would love to hear from you! Send us your questions, comments & suggestions.

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Your personal information is always confidential.

The NARCOMS Global MS Patient Registry facilitates multi-center research on multiple sclerosis, developing collaboration between MS centers of excellence throughout the world to increase knowledge, improve clinical care, and enhance the quality of life for persons with MS.

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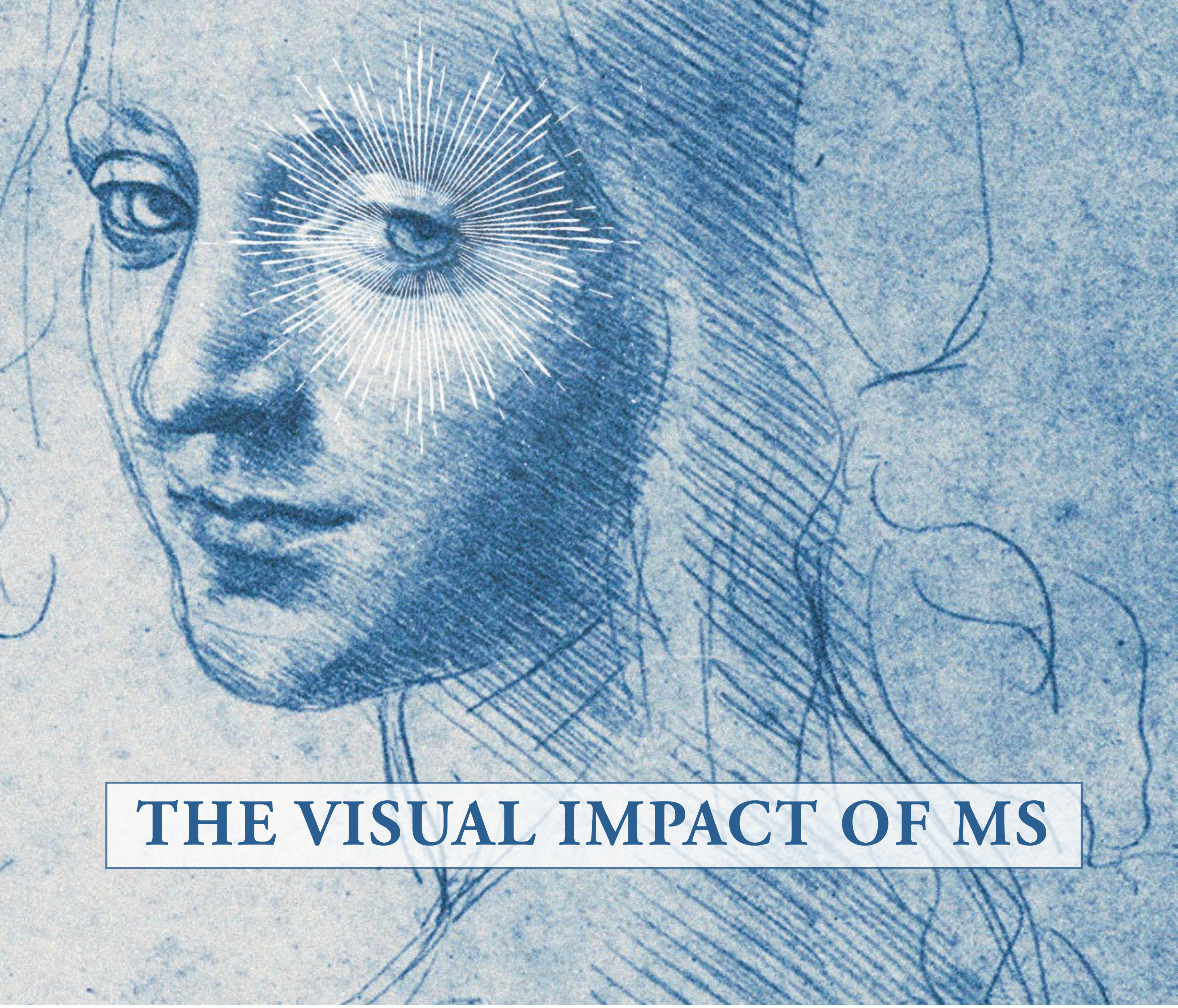
If possible, please use pen rather than pencil when filling out NARCOMS paper surveys. Responses are scanned to electronic files for data capture and pen is easier to read. Thanks!



THE VISUAL IMPACT OF MS

You're walking through the mall doing some last-minute holiday shopping when you notice that the usually vivid colors of the season don't seem quite as bright as normal. You've noticed that your vision in one eye keeps going "fuzzy," especially when you have been looking at a screen for a long period of time—only blinking doesn't clear it up.

If it happens once, an episode like this may be normal, however recurrent eyesight problems are not something to be taken lightly. In fact, vision issues are among the most frequently cited first symptoms causing individuals to see a doctor, and eventually leading to a diagnosis of multiple sclerosis. Because MS is a disease of the central nervous system, it can affect the optic nerve, which transmits light and visual images to the brain. Almost 70 percent of people with MS will have an episode of optic neuritis (see below), according to the MS Trust, and Everyday Health says as many as 80 percent of MS patients will experience vision problems.

THERE ARE THREE VISUAL DISORDERS COMMONLY ASSOCIATED WITH MS:

- **Optic Neuritis**—Optic neuritis is defined as inflammation of the optic nerve or lesions along the nerve pathways that control eye movements and visual coordination. Dark spots, or scotoma, may appear in the center of the visual field, or patients experience blindness in one eye or blurring or graying of vision. Optic neuritis can be treated with oral or intravenous steroids.

- *Risk factors for developing optic neuritis include:* Age—most often occurring between ages 20 to 40. Women are much more likely to develop optic neuritis than men. In the United States, whites experience optic neuritis more than blacks. Certain genetic mutations might increase risk of developing optic neuritis or MS.

- **Nystagmus**—Nystagmus is uncontrolled horizontal or vertical eye movements, or "eye tremor." It may occur only when the person looks to the side, or it may be severe enough to impair vision. Some medications and special prisms have been reported to be successful in treating the visual deficits caused by nystagmus and a related eye-movement disorder, opsoclonus, which causes "jumping vision." A form of oscillopsia, nystagmus can cause dizziness and or vertigo. [For more on other types of tremors, see "MS Reflections," page 10.]

- **Diplopia**—Defined as double vision, diplopia occurs when the pair of muscles that control eye movement aren't coordinated due to weakness in one or both pairs of muscles. As a result, images align and the person perceives a false double image. Diplopia may increase with overuse of the eyes (due to reading or computer use, for example) or fatigue, and may improve with rest. It usually resolves without treatment, but in certain cases an eye patch may be worn, or steroids recommended.

These disorders can also be exacerbated by heat. The good news? Vision impairments related to MS are often temporary, and complete vision loss is rare—but possible without treatment—so see your MS or eye care provider if you are experiencing any changes in vision. It is important to note that early treatment for first incidents of optic neuritis with corticosteroids can delay conversion to multiple sclerosis. To read more, visit: **http://tinyurl.com/glvcq5o**

Vision Research in MS

Recent research has explored the use of optical imaging as a tool to track disease progression in MS. A team of 15 investigators at 6 institutions used a tool called Optical Coherence Tomography (OCT), partnered with MRI brain scans, to track the impacts of MS and determine whether changes in nerve layers at the back of the eye mirror changes in MRI-detected brain tissue degeneration and integrity.

OCT is a non-invasive, well-tolerated, and relatively inexpensive imaging method that scans the nerves in the back of the eye. The research team hypothesized that because typical MRI does not have the power to see or track shrinkage in specific areas of the brain, use of OCT may make up for the things the MRI cannot detect.

"Mounting evidence suggests that damage to nerve cells underlies long-term progressive disability in people with MS. So having easier ways to detect and track nerve degeneration would help speed the search for better therapies," reports the National Multiple Sclerosis Society in an article about the research results: **http://tinyurl.com/jmo7h39.**

The team conducted OCT scans twice a year and MRI brain scans once a year on 107 people with relapsing-remitting, secondary progressive or primary progressive MS. At the end of four years they reported that OCT findings reliably reflected overall brain degeneration, with a specific layer of the retina showing shrinkage (atrophy) at similar rates as specific brain regions seen with MRI. These similar rates of atrophy were more strongly associated in progressive MS for most areas of the brain. The American Academy of Neurology reported the results of this four-year study in its publication, *Annals of Neurology* in November 2015. Three of the research team members won the Barancik Prize for Innovation in MS Research for this work using OCT to study MS.

A recent paper published in *The Lancet Neurology* in March 2016 suggests using OCT in patients with MS without previous optic neuritis as markers of neuronal degeneration and disability (Elena Martinez-Lapiscina and colleagues in *The Lancet Neurology*.) The NMSS funded another study into OCT use for tracking of MS disability progression, conducted at the University of Wisconsin, Madison. The researchers found physical evidence, in a lab model, linking actual damage to the myelin coating on nerve fibers in the optic nerve, and nerve fiber damage, with readings from OCT scans in a lab model.

This means that OCT changes seen at the back of the eye reflect actual damage to the optic nerve. Study authors claim this work provides independent evidence confirming the value of OCT as an indicator of nerve health and loss, and potentially progression of MS and other disorders.

Several universities in the United States have established **neuro-opthalmology** programs specializing in the diagnosis and management of patients with neurological disorders that affect vision and eye movements, including MS. One such program at the University of Pennsylvania is conducting research on:

- The validation of new measures of visual function, to be used in clinical trials in MS, including low-contrast letter acuity (measure of vision function in low-contrast environments)
- The role of OCT in clinical trials to treat optic neuritis and MS
- New therapies for acute optic neuritis, being tested in a mouse model of MS called autoimmune encephalomyelitis

Similar research is being conducted around the U.S. by neuro-opthalmology departments at Emory University, Johns Hopkins University, the University of Iowa, and the University of Michigan, among others.

Options for Vision Improvement

There are possibilities for improving quality of life with vision issues, research shows. In-home visits by visual rehabilitation specialists can make a significant difference for patients with low vision, according to a recent study from Cardiff University's School of Optometry and Vision Sciences, United Kingdom. Study participants had in-home visits over six months, which included assessments in areas such as functional vision, lighting, personal hygiene, medication management, kitchen safety, household tasks, welfare entitlements, emotional difficulties, orientation and communications.

Training and support was then tailored within these areas, for example, support in the use of low vision aids, medicine organization, and long cane training. The visual rehabilitation officer determined the number of visits on a case-by-case basis. About 70% of people in the home visit group reported that the visits were "extremely helpful," with kitchen training highlighted as the most helpful aspect.

Exercise may also play a role in improving visual function in those experiencing vision impairment in MS, according to some early research. One study showed that the number of steps taken per day was associated with greater retinal nerve fiber layer thickness and total macular volume in persons with MS, as measured by OCT. Drs. Rob Motl and Brian Sandroff, then at the University of Illinois at Urbana-Champaign, conducted a study in 84 participants with MS, without ocular disease or high myopia. They underwent a neurological examination for Expanded Disability Status Scale (EDSS) scoring, followed by OCT, then wore an accelerometer during the waking hours of a 7-day period to objectively measure physical activity as steps per day.

Physical activity was associated with integrity of the anterior visual pathway, assessed by OCT, in persons with MS, and this association was independent of sex, MS subtype, disease duration, disability, and visual function. The researchers encourage additional studies to exam the causal nature of the association between physical activity and markers of the visual system in MS.

Vision is an important aspect of health, affecting quality of life. Future research is needed to determine how vision issues and screening may offer insights into MS. Make your healthcare provider aware of any changes you may experience with your vision.

Resources for Vision Impairment and MS:

- **Multiple Sclerosis Association of America**: www.mymsaa.org/ms-information/symptoms/visual-disorders/
- **National Multiple Sclerosis Society**: www.nationalmssociety.org/Symptoms-Diagnosis/MS-Symptoms/Vision-Problems
- **Everyday Health**: www.everydayhealth.com/multiple-sclerosis/symptoms/eye-complications-ms/
- **National Library Service for the Blind and Visually Handicapped**: www.loc.gov/nls/
- **WebMD**: Multiple Sclerosis: Early Warning Signs
- **North American Neuro-Opthalmologist Society**: Find a Neuro-Opthalmologist

For first-person stories of individuals living with MS and vision issues, visit **MultipleSclerosis.net** and search for "Vision."

NARCOMS Q&A

Q: I have been participating in this research survey for over a decade and I'm not sure you read the comments but I've said this in the past and I'll say it again:

The phrasing of disability questions does not allow for the fact that many, if not most, people with advanced MS use some kind of ADL or assistive technology to complete tasks. Asking if fatigue, hand function, bowel-bladder issues etc. prevents us from doing some/none/all of our tasks is not a fair question.

I'm able to do 90% of the things I want to do in a day but I can't do them without some sort of assistive device. So how do I answer this question accurately?

My hand function does not prevent me from doing most of my tasks because I have ADLs, I take medications, I have assistive technology. To wit, I have very limited hand function but I had no trouble writing this because I use assistive technology.

A: Thank you for your continued dedication to NARCOMS! We read all of the comments submitted with the surveys, and your comments are really important for several reasons. First, they help us make the survey better. Second, they help us think of new research questions and topics of interest to you. Third, they help us choose topics for the magazine. So please, keep telling us what you think and keep sending in suggestions!

The disability questions are focused on your level of ability without assistance. This helps to determine the current status of disability. Knowing this over time helps researchers learn about when disability occurs in the course of MS. It is important that you continue to answer these questions without considering the use of assistive devices.

How you function in your daily life with assistance is also important. However, use of devices is a slightly different area of research than disability level. For example, the "MS Apps" section in this issue lists assistive technologies for those with visual difficulties (page 18). Some people use page-turners for reading, or voice technologies for writing, or devices to help their mobility.

Previous surveys have asked about the need for assistance with daily activities, most recently in the Spring 2016 Update. In the Fall 2013 Update we asked the types of assistive devices used. Asking this level of detail in each survey would make the survey very long but we are considering a shorter question about whether you use devices to be included in regular updates.

Thank you so much for the suggestion!

As always, if you have any questions about other projects or research that sounds interesting, please let us know!

SURVEY 101 ////

NARCOMS VISION RESEARCH

In each NARCOMS update survey, participants are asked to given their current disability level overall in the Patient-Determined Disease Steps (PDDS) , and in several areas with the Performance Scales (PS). One of the scales is the Visual PS, which ranges from 0–Normal Vision to 5–Total Visual Disability (see "Snapshot," page 15). This scale is captured at enrollment and in every update so that researchers can determine how vision changes over time and how visual impairment relates to other disabilities in MS and the overall quality of life.

Three research projects since 2011 have focused on vision and visual disabilities:

In 2011, Dr. Ruth Ann Marrie, Scientific Director of NARCOMS, and co-authors reported in, "Substantial adverse association of visual and vascular comorbidities on visual disability in MS," that 16% of NARCOMS participants reported a current visual disease or disorder, like cataracts or glaucoma. Those with other vascular disease, like diabetes or hypertension, were at higher risk of vision issues and noted that vision issues were associated with an increased risk of "falls, fractures, and depression." The authors suggest, "MS patients should undergo regular ophthalmologic (eye) assessments to identify treatable visual disorders which may increase visual disability if undetected."

In 2012, Dr. Amber Salter and co-authors reported in, "Seeing in NARCOMS: a look at vision-related quality of life in the NARCOMS registry," that a prior history of visual disorders such as optic neuritis and diplopia were associated with increased visual impairment. Higher visual impairment can substantially impact quality of life and make daily activities more difficult. These authors suggest, "treatment of visual comorbidities could potentially delay progression of visual impairment and improve QOL [Quality of Life]."

In 2015, Dr. Robert Fox, NARCOMS Medical Director, and co-authors reported in, "Prevalence of multiple sclerosis symptoms across lifespan: data from the NARCOMS Registry," that "Some symptoms (vision, cognition, sensory, pain, depression) were relatively common early on in multiple sclerosis, but did not appear to be more frequent with longer disease duration."

Bottom line? Taking care of your eye health helps to take care of your whole health! Make sure to ask your healthcare provider about taking care of your eyes.

Should you ever have a question about NARCOMS or an update survey, please call or email us at: 1-800-253- 7884 (toll-free US) and narcomsnow@narcoms.org.

Symptomatic Management of Multiple Sclerosis–Associated Tremor Among Participants in the NARCOMS Registry

William Meador, MD; Amber R. Salter, MPH; John R. Rinker II, MD

Published in the International Journal of Multiple Sclerosis Care (IJMSC) in May/June 2016,
ijmsc.org/doi/full/10.7224/1537-2073.2015-008?=&code=cmsc-site

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As many people who live with Multiple Sclerosis (MS) are well aware, effective and well-tolerated medical options for the management of many symptoms in multiple sclerosis can be hard to find. One symptom that is particularly common and difficult to manage in MS is tremor. Published research reports the frequency of tremor in MS patients between 25% and 58% with up to 15% of MS patients living with moderate or severe tremor. These same studies have shown that tremor is related to a higher rate of neurologic-related disability and reduced quality of life. For such a common and potentially disabling symptom, tremor is very rarely studied in multiple sclerosis.

A research team at the University of Alabama at Birmingham (UAB) wanted to investigate how patients living with multiple sclerosis–related tremor attempted to manage this symptom with the help of their physician. NARCOMS participants who reported tremor in their annual surveys were sent additional surveys with questions focused on their tremor, the impact of the tremor on their daily function and quality of life, and the treatment(s) they utilized to help with this symptom.

More than 500 NARCOMS participants returned completed surveys. Just under half of those who responded to the survey and reported tremor (238; 46.9%) reported taking medication to manage their tremor symptoms. Symptomatic drug use was more likely in participants reporting moderate (53.9%) or severe (51.3%) tremor than in those with mild (36.6%) or totally disabling (35.0%) tremor. The researchers believe that this reflects several things:

1. MS tremor remains undertreated and under-recognized by treating physicians
2. MS tremor is difficult to treat
3. The medications used to treat MS tremor carry side effects that often outweigh the modest benefit.

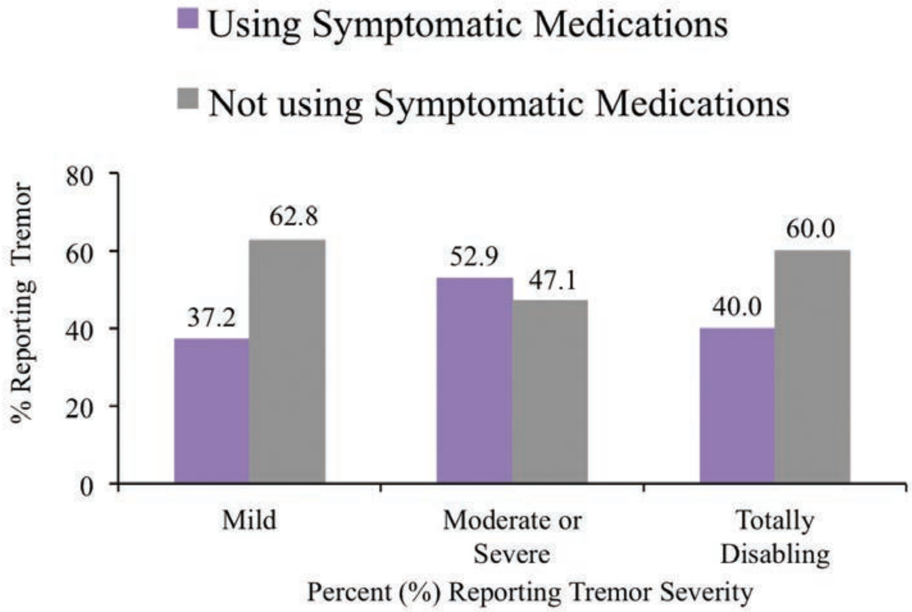
Respondents who reported the use of symptomatic medications for their tremor were more likely to not be working and were more likely to have more severe tremors. Interestingly, patients who had moderate or severe tremors were more likely to use a medication to control their tremor than those with mild or disabling tremors (Figure 1).

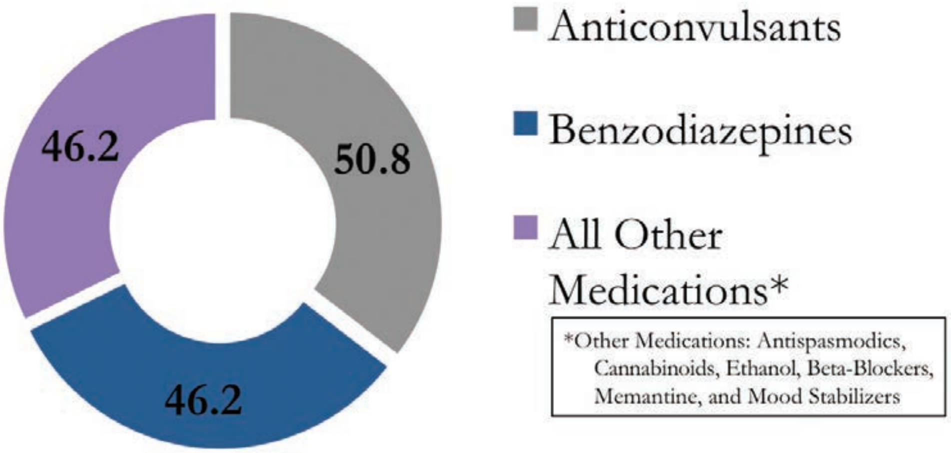
This may reflect the fact that mild tremors are not disruptive enough to warrant medication and once a tremor is disabling, the doses of medications required to help the tremor may produce intolerable side effects. We also asked respondents which medications they used to try to treat their tremor. Nearly two-thirds of respondents reported using only one medication to control their tremor while the others used two or more medications.

Of the types of medications used, respondents reported overwhelmingly that they used either anticonvulsant medications—medications originally designed for seizures—and/or benzodiazepines, for example lorazepam, diazepam, clonazepam (Figure 2). These classes of medications appear to be the most frequently prescribed in MS patients with tremor. This may reflect a bias of the treating physician to use medications with which she or he is familiar, or it may reflect an attempt to use medications which may help both tremor and other symptoms, such as pain or spasms.

These findings confirmed that when tremor is present in multiple sclerosis, it commonly contributes to disability and reduced quality of life. We also found that most patients do not take medications that help their tremor. These results, combined with other research, such as Koch, et al, support the notion that MS tremor is difficult to treat and warrants further study, as it significantly contributes to disability.

Figure 1.





*Other Medications: Antispasmodics, Cannabinoids, Ethanol, Beta-Blockers, Memantine, and Mood Stabilizers

Figure 2.

Percent (%) Type of Medication Reported to Improve Tremor

Primary and Secondary MS Research Took Center Stage at ECTRIMS 2016

The European Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS) held its 32nd annual meeting in London, September 14–17. With more than 9,000 attendees, it is the world's largest MS conference, where global researchers, students, and professionals converge to present and learn about the latest MS research. Following are some highlights from this year's event.

Secondary Progressive MS Participants See Positive Results from Fingolimod-like Drug

In a phase III clinical trial called EXPAND, siponimod (Novartis), a drug similar to fingolimod (Gilenya®) but with a more targeted effect on white blood cells, slowed MS disease progression more than placebo. Siponimod may have fewer side effects than fingolimod, while maintaining similar positive effects.

The trial included 1,651 participants from 31 countries making it the largest clinical trial on people with secondary progressive MS. (*Ludwig Kappos et al, abstract 250*) Participants received either a daily placebo or siponimod tablet. Results presented at ECTRIMS showed that, after 3 and 6 months, people with MS who received siponimod had slower progression as assessed by Expanded-Disability Status Scale (EDSS). Novartis has announced it will apply for the regulatory approval to formally include this drug as a treatment for secondary progressive MS. The results of this study have been submitted for publication. Read more about this trial on the International Progressive MS Alliance website: http://tinyurl.com/hu8comm.

Lipoic Acid for Neuroprotection in Secondary Progressive MS

Researchers from Portland, Oregon, presented the results of a small clinical trial testing the effects of lipoic acid on 54 participants with secondary progressive MS. Lipoic acid is a tablet with antioxidant effects available over the counter. *(Rebecca Spain, abstract 222)*. Participants were divided into two groups who either received placebo or lipoic acid. After 96 weeks of follow-up trial results showed that the group who received the lipoic acid treatment had lower rate of brain atrophy than those in the placebo group. However, there was no significant effect of the treatment on disability and clinical measures in people who received the treatment. Study authors stressed the need for trials with more participants in order to prove the effectiveness of lipoic acid.

Secondary Progressive Drug Trial MS-SMART Reports on Recruitment Phase

The MS-SMART drug trial (Multiple Sclerosis – Secondary progressive Multiple Arm Randomisation Trial) is an ongoing study in 13 sites across the United Kingdom testing three drugs at once: amiloride, licensed to treat heart disease; fluoxetine, licensed to treat depression; riluzole, licensed to treat motor neuron disease (MND). Three research abstracts reported on the trials' recruitment: A total of 440 participants with worsening secondary progressive MS have been recruited in 4 groups: (1) placebo, (2) riluzole, (3) fluoxetine, and (4) amiloride. Investigators plan to follow participants for 96 weeks and assess the effects of each drug on clinical, disability and MRI outcomes. *(Peter Connick, abstract P1203)*.

Update on the ORATORIO Trial on Ocrelizumab for Primary Progressive MS

ECTRIMS 2016 was the setting for the first positive results from the drug ocrelizumab for people with primary progressive MS in a multi-center, multinational drug trial called ORATORIO. Several groups presented data on the drug this year, showing consistent positive effects on walking and slowing disability progression. The most common adverse effect is reaction at injection site. *(Jerome De Seze et al, poster 720; Gavin Giovannoni et al, poster 746; Jerry Wollinsky et al, poster 1278; Jerome De Seze et al, poster 1279).*

Mouse Gene Mapping May Lead to Alternative Treatments for MS

Interferon-beta therapies (e.g. Avonex®, Betaseron®) have long been used as a treatment for multiple sclerosis, but they can be costly, painful, and sometimes ineffective. New research from Duke University on mice may point to new drug candidates that might help MS patients when interferon beta fails. The researchers studied an MS-related disease in mice and were able to map out biological mechanisms that can lead to a nonresponsive form of MS.

“The study shows a really clear molecular mechanism that may explain why some people do not respond to interferon-beta treatment,” said Mari Shinohara, an associate professor of immunology at Duke and a senior author on the study, available online in the journal *Nature Neuroscience*- http://tinyurl.com/jae4wf9. “We’ve found what makes a difference in the response.”

One challenge in treating MS is understanding the biological mechanisms that lead to damage caused by deterioration of myelin, the protective coating covering neurons. Another challenge is the recent discovery that those mechanisms may vary in each patient according to genetic and environmental factors.

In 2012, the researchers found that interferon-beta works in mice by inhibiting an immune protein complex called the NLRP3 inflammasome. This same study, however, found that some mice missing this protein complex still got sick, and for them interferon-beta treatment was ineffective. This study was aimed at determining how the disease was triggered in those missing the protein complex.

“We knew the second pathway bypassed the NLRP3 inflammasome,” Shinohara said. “So the question became, what is actually involved?” The team found two genetic receptors, called CXCR2 and LTBR, were central to the development of the disease in the mice who did not respond to interferon-beta. They also found that treating the mice with a molecule that blocks these receptors improved their symptoms.

“We found that, depending on which type of disease the mice had, we could choose the appropriate treatment,” Shinohara said.

To compare the effects in humans the team then used data gathered as part of the MURDOCK MS study to compare the genetic profiles of MS patients who responded to interferon-beta treatment with those who didn’t.

“We identified individuals who were not responsive to the interferon-beta treatment, and looked at their CXCR2 and LTBR” genes, said Simon Gregory, a professor of medicine and molecular genetics and microbiology at Duke and a co-author on the paper. “We found them to be upregulated,” meaning they were producing more of the receptors, he said.

These clinical trials are designed to study vision-related issues in multiple sclerosis.

Study and Treatment of Visual Dysfunction and Motor Fatigue in Multiple Sclerosis

Purpose: Primary fatigue represents a major cause of disability in patients with multiple sclerosis (MS), being reported in about 90% of cases. Fatigue interferes with everyday functioning but, unfortunately, little is known about its mechanisms. The investigators propose a characteristic eye movement abnormality (internuclear ophthalmoparesis, INO), commonly encountered in MS, as a simple model for primary motor fatigue. The investigators described worsening of ocular performance in MS patients with INO following visual tasks (ocular motor fatigue), which is likely due to decreased neural conduction along brain pathways injured by MS. This mechanism could represent a major component of MS-related primary motor fatigue.

Rationale: Relevant to Veterans' care, INO is a significant cause of visual disability, especially when complicated by ocular fatigue, and limits daily activities such as reading and driving. The investigators propose a medical treatment to improve ocular performance/fatigue in INO, which can reduce visual disability and improve quality of life in Veterans with MS.

Eligibility: Age 18 to 65, male or female, with a diagnosis of MS of any course and duration, and evidence of mild to moderate internuclear opthalmoparesis (INO). Further enrollment criteria are available at: http://tinyurl.com/jbujvts.

Study Design: Interventional study administering the drug Dalfampridine over a 10-week period.

Sponsor: VA Office of Research and Development

Contact: Alessandro Serra, MD, PhD
(216) 791-3800 ext. 5218,
alessandro.serra@va.gov

Vestibular Rehabilitation for Persons with Multiple Sclerosis: Who Benefits Most? (MSVR3 Trial)

Purpose: To advance our knowledge of the effect of vestibular rehabilitation for persons with MS in a larger study identifying persons with MS who have brain lesion involvement in areas that control balance and eye movement.

Eligibility: A diagnosis of MS, 18–60 years old, reporting moderate fatigue and impaired balance. Further eligibility criteria are at: http://tinyurl.com/zdxldhl.

Study Design: Participants who are randomized to the experimental group will perform 1-hour supervised intervention sessions 2 times/week for 6-weeks, then 1 time/week for 8-weeks, for a total of 20 supervised sessions. The intervention is a progressive vestibular rehabilitation program comprised of balance and eye movement exercises as detailed in our preliminary study report.

Study Outcomes: Balance, visual stability, perceived fatigue.

Sponsor: University of Colorado, Denver; National Multiple Sclerosis Society

Contact: Maggie Reineke, (303) 724-4717, Maggie.Reineke@ucdenver.edu; Jeffrey Hebert, (303) 724-9595, Jeffrey.Hebert@ucdenver.edu

SnapShot

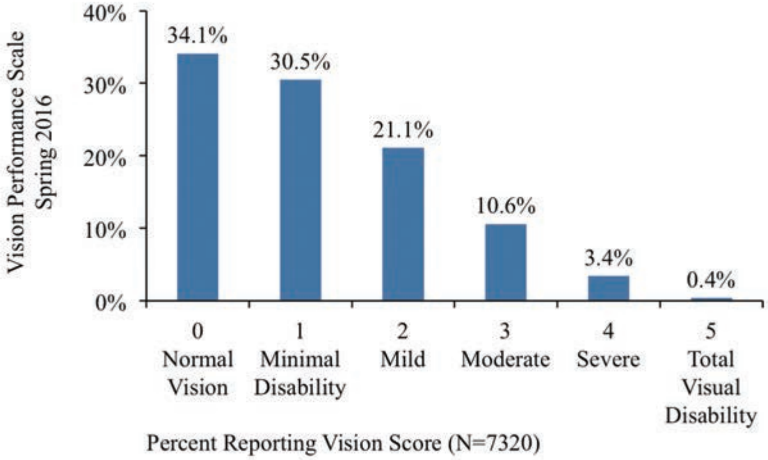
Spring 2016 Summary of Responders

More than 7,500 NARCOMS participants completed Spring 2016 Update surveys! The average age of survey responders was 60 years. Responders ranged in age from 19 to 96 years old. Half of responders had lived with MS for at least 19 years. Some responders were newly diagnosed, while others had lived with MS for more than 70 years. Responders reported their degree of difficulty with walking. One in four participants reported normal or mild disability. One in four participants reported that they need two canes, two crutches or a walker.

Vision Performance Scale

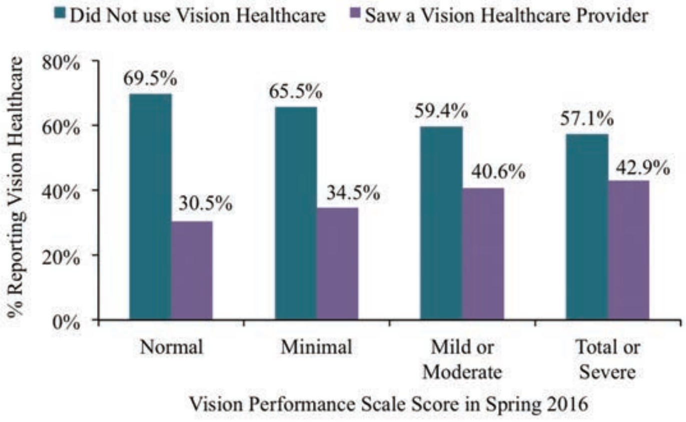
Over 7,300 participants told us about their vision using the Vision Performance Scale:

- Over 1/3rd of all responders reporting Normal vision
- Half reporting Minimal or Mild Visual Disability
- Fewer than 5% reporting Severe or Total Visual Disability



Use of Vision Healthcare

Over 90% of responders reported seeing at least one healthcare provider between November 2015 and April 2016. Of those, 38% reported using a vision healthcare provider: 20.4% reported seeing an ophthalmologist and 14.3% saw an optometrist, and 3.3% saw both types of eye care providers.



While most respondents did not use any vision healthcare, participants with higher vision scores were more likely to report having seen either an ophthalmologist or optometrist compared to those with lower vision scores.

Understanding how often persons with MS visit eye care professionals can help inform MS care providers about the overall health of their patients.

MS Messenger

Twenty-First Century Cures Act Passes Congress, to Be Signed into Law

A $6.3 billion bill that speeds up drug approvals, funds research in cancer and brain science, strengthens mental healthcare, and combats opioid abuse won approval in the Senate on December 7, and now goes to President Barack Obama for his promised signature. The 21st Century Cures Act, passed the House of Representatives in an overwhelming victory 392 to 26 vote, and passed the Senate, 94 to 5.

Many medical societies supported the bill, including the American Psychiatric Association, the American Society of Clinical Oncology, and the American Gastroenterological Association, the American Heart Association, the Arthritis Foundation, the Association of American Medical Colleges, and the Pharmaceutical Research and Manufacturers of America, the trade group for drug makers.

The National Institutes of Health (NIH) will receive the bulk of the money—$4.8 billion— for research that includes the Cancer Moonshot, the Precision Medicine Initiative, the Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative, and regenerative medicine.

“The passage of the 21st Century Cures Act will accelerate the discovery, development, and delivery of life-changing treatments and improve the day-to-day lives of people with multiple sclerosis,” said Cyndi Zagieboylo, President and CEO of the National MS Society.“I applaud Congress for creating a pathway for promising innovation through the establishment of a data collection system for neurological diseases; providing new funding for the National Institutes of Health and the Food and Drug Administration; protecting access to power complex rehabilitation technology wheelchair accessories and more. This groundbreaking legislation truly brings us one step closer to ending MS.”

Read the NMSS press release on the bill here - http://tinyurl.com/hjay68a

NARCOMS at ACTRIMS Forum

actrims
2017 FORUM

In February, CMSC/NARCOMS Fellow Katherine Fitzgerald, PhD, will present her research on NARCOMS data about the effect of specific diets on multiple sclerosis symptoms the Americas Committee for Treatment and Research in Multiple Sclerosis (ACTRIMS) Forum meeting in Orlando, Florida.

Fitzgerald will present a poster, “Prevalence and User Characteristics of Specific Diets in People with Multiple Sclerosis,” at the poster session at 7pm on Thursday, February 23.

NARCOMS Publications in 2016

In addition to presenting NARCOMS research at meetings in Spain, Canada, and the US, NARCOMS researchers published 10 papers using the data provided by participants. The topics ranged from statistical models used for predicting disability, to insurance changes, to DMT use and progressive MS. All abstracts are freely available on the NARCOMS bibliography on the US National Library of Medicine PubMed.gov website: **http://tinyurl.com/zmh3wfs**

1. **Bethoux and Marrie:** A Cross-Sectional Study of the Impact of Spasticity on Daily Activities in Multiple Sclerosis (Lead Author: F Bethoux).
2. **Cofield et al:** Disability Progression After Switching from Natalizumab to Fingolimod or Interferon-Beta/Glatiramer Acetate Therapies: A NARCOMS Analysis
3. **Freeze et al:** Understanding Lifestyle Decisions based on patient historical data: A Latent Growth Modeling Approach (not available online, textbook chapter).
4. **Kinnett-Hopkins et al:** Social Cognitive Correlates of Physical Activity in Black Individuals With Multiple Sclerosis
5. **Liu et al:** Relationship Between Symptom Change, Relapse Activity and Disability Progression in Multiple Sclerosis.
6. **Meador et al:** Symptomatic Management of Multiple Sclerosis-Associated Tremor Among Participants in the NARCOMS Registry (see “MS Reflections”, p10).
7. **Salter et al:** Examining the Joint Effect of Disability, Health Behaviors, and Comorbidity on Mortality in MS
8. **Schwartz et al:** Refining a Web-based goal assessment interview: item reduction based on reliability and predictive validity.
9. **Sidovar et al:** Mapping of Multiple Sclerosis Walking Scale (MSWS-12) to five-dimension EuroQol (EQ-5D) health outcomes: an independent validation in a randomized control cohort.
10. **Wang et al:** Health insurance affects the use of disease-modifying therapy in multiple sclerosis.(See *NARCOMS Now*, Fall 2016 “MS Reflections”)

MS APPS (& BLOGS)

In this issue of "MS Apps & Blogs" we are examining apps that deal with vision impairment, and tools to assist with it; plus tools to simulate vision issues and better understand them.

Help with macular degeneration or other eye issues associated with deterioration or damaged:

Amsler Grid App (Android)
This app can help test and monitor vision changes related to macular degeneration or other distortion in your vision field resulting from damage to the macula (a spot in the back of the eye).
http://tinyurl.com/moqf5qo

MaculaTester (Apple)
If you're using an Amsler grid to keep track of vision changes related to macular degeneration or other eye diseases, this interactive version goes a couple of steps further: It will record the areas of distortion that you see on the grid, so you can show them to your eye doctor. It also reminds you when it's time to take the test.
http://tinyurl.com/z2jj7u8

VisionSim (Apple)
The Braille Institute developed this app to let people with healthy vision see what the world looks like to someone with macular degeneration, diabetic retinopathy, glaucoma or cataracts. It uses the camera in your device and applies special filters to the scene to simulate the symptoms of the disease.
http://tinyurl.com/js6og9y

Distinguishing between colors: People with different types of color vision deficiency perceive colors differently (think red-green colorblindness). The colors which can be recognized or distinguished by color deficient persons are different from color normal persons. Such conditions may occur from birth, an illness, or chronic condition.

Chromatic Glass (Apple) is a color vision assistance tool for persons who have difficulty recognizing specific colors or perceiving differences between specific color pairs due to a color vision deficiency.

This app helps users to recognize and distinguish such colors by making a special modified color image based on scientific methods in real-time and displaying it and the original image alternately.
http://tinyurl.com/j6q5gxv

Color Vision Test Pro (Apple) offers a color blindness test and colorblindness simulator. It offers optical illusions, computer generated images, and visualizations to train your eyes. It uses the phone's camera to help determine colors under different settings.
http://tinyurl.com/jc63jzq

Editor's Note: *NARCOMS does not endorse any of these programs as a medical tool or diagnostic device; if you are experiencing vision issues, please see your healthcare provider.*

Need help with magnification or seeing what you are reading more clearly? There are a number of apps designed to help magnify and provide light to what you are reading:

iRead

This magnifier app was designed by an ophthalmologist and includes the ability to light your reading material, such as a menu in a dim restaurant.

(Apple) **http://tinyurl.com/zcokv4q**
(Android) **http://tinyurl.com/zcy6nrg**

Magnifying Glass (Android)

Just launch the program and point your phone to the object you are viewing, and this will magnify it. The application has a light as well, which activates only if your phone or tablet has a flash. It can also freeze-frame what you're viewing, so you don't have to keep holding the device steady while you read.

http://tinyurl.com/qdof68z

Magnifying Glass With Light (Apple)

Much like the Magnifying Glass app for Android phones, this handy app for Apple devices is great for magnifying small font on menus, medicine bottles, receipts and more, and features an adjustable flashlight option.

http://tinyurl.com/ju8pzfk

If you have or are anticipating vision impairment beyond magnification issues or want to assist someone you know with this type of vision issue:

Be My Eyes (Apple)

This app can assist vision impaired people with important, everyday tasks like reading labels or receipts. You can choose to be a helper or sign up to be assisted if you are vision impaired.

http://tinyurl.com/mocee6a

Pocket Braille (Apple)

An app to learn Braille, including the alphabet, numbers, contractions and one- and two-cell word signs.

http://tinyurl.com/j3mgb8o

NantMobile Money Reader (Apple)

This app uses the iPhone's camera to recognize currency, telling you the denomination in real time, without the need for an Internet connection. It helps make sure you're paying the proper amount at the register and can also check that you receive the right amount of change. At last update the app supported 21 currencies. English, Spanish, French, Italian, German and several other languages are available for the voice-over feature.

http://tinyurl.com/h2whzvz

Everyday eye health: Want to keep an "eye" on your vision? The free **EyeXam** app for smartphone or tablets lets you test your vision against the 20/20 benchmark and also includes tests for color perception, astigmatism and eye dominance. It is available for Android or Apple devices.

EyeXam for Android » **http://tinyurl.com/grtvbnu**
EyeXam for Apple devices » **http://tinyurl.com/zlmxkz4**

play

Find the following hidden words:

family, cheer, laughter, wishes, goals, celebration, gratitude, peace, friendship, rest, renewal, relaxation, dreams, support, happiness, health

Q	H	X	B	H	I	L	I	Q	M	P	B	E	S	F	S
E	O	A	L	E	C	S	S	G	W	W	D	D	A	Y	F
M	S	T	P	E	A	C	E	G	M	C	U	M	P	E	H
L	R	P	R	P	I	H	S	D	N	E	I	R	F	Y	O
N	D	Y	N	O	I	T	A	X	A	L	E	R	L	T	I
C	A	I	O	T	P	N	X	Y	Y	E	G	A	C	Y	G
R	H	X	Y	T	O	P	E	A	S	B	M	E	E	M	W
A	V	E	H	H	R	E	U	S	L	R	G	D	A	E	D
O	R	D	E	T	E	I	E	S	S	A	U	T	S	E	R
U	P	W	E	R	L	F	F	C	E	T	W	X	F	V	M
P	I	O	E	S	A	A	Z	Z	I	I	I	E	G	D	S
W	R	Z	C	X	S	A	E	T	S	O	W	T	N	R	K
X	A	E	E	L	G	A	A	H	I	N	Z	R	G	E	R
E	B	S	A	S	R	R	E	T	H	G	U	A	L	A	R
T	M	O	L	J	G	S	A	X	S	P	G	C	E	M	L
H	G	F	K	I	U	R	D	K	N	T	X	U	J	S	T

FIND THE ANSWERS TO THIS WORD PUZZLE ONLINE:
www.narcoms.org/narcomsnow/play/answers

FACES of NARCOMS

Snowbird Finds Solace in the Southwest

I was 47 years old when I was diagnosed with MS, a disease I knew nothing about. After learning about MS and its many symptoms, I realized my first MS attack had occurred when I was 33 years old, following a move from my native California to St Louis, Missouri. My symptoms back in 1979 were severe fatigue and depression, which I attributed to stressful life situations at the time.

Then in 1993, tingling in my feet and both legs prompted me to see an orthopedic specialist. X-rays revealed arthritis but the rest of my spine was unremarkable. Then I called the doctor I'd seen in 1979 (who was not covered by my health insurance at the time). He reviewed my past chart and examined me, noting my change in gait and leg weakness. He suggested I might have MS and advised me to see a neurologist.

The neurologist ordered a number of tests but didn't think it was MS. Optic neuritis diagnosed by my ophthalmologist sent me back to the neurologist who said my MRIs were negative for MS and ordered an HIV test. When that was negative, he ordered a spinal tap, which resulted in an excruciating headache. I was then referred to a pain specialist who recommended I find another neurologist.

An MS diagnosis was finally made when the spinal tap were evaluated and I saw a new neurologist at a different medical facility. The first thing this new doctor asked was, "What's been going on in your life?" and he listened to me! He told me about the first medication for relapsing-remitting MS and I was added to the lottery for this new injectable drug, Betaseron. I am still a patient of my compassionate, understanding neurologist 22 years later.

In 2011, we purchased a winter home in Southern Arizona. After six months in the sunshine and low humidity, I told my neurologist I felt better than I had in more than 30 years. An MRI showed no sign of active MS and the majority of my symptoms were gone. I stopped taking Betaseron after 18 years but continued seeing the neurologist every six months and each of my MRIs have remained clear.

At 69, I have more energy than I can remember since college. I can't say if taking Betaseron along with many hours of exercise and physical therapy, or if winters filled with sunshine, minimal humidity and lack of stress, or nutritional supplements for 30+ , or essential oils for 6 years has kept me stable but the Grace of God is definitely part of these wonderful four years of remission.

—L. Garrett
St. Louis, MO

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