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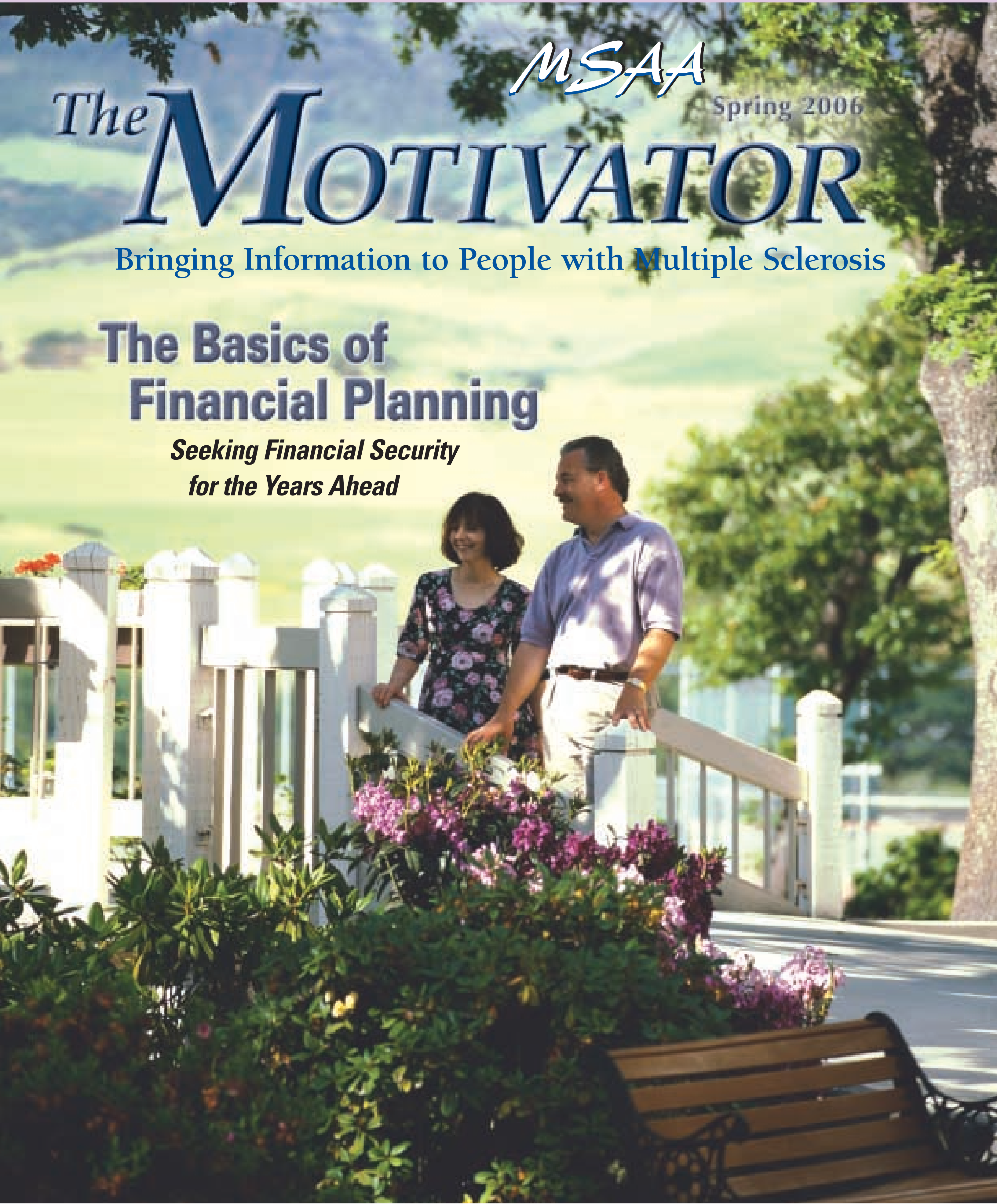
MSAA

The MOTIVATOR

Spring 2006

Bringing Information to People with Multiple Sclerosis



The Basics of Financial Planning

Seeking Financial Security for the Years Ahead

The MSAA Motivator

Published by the Multiple Sclerosis Association of America

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The Multiple Sclerosis Association of America's mission is to enrich the quality of life for individuals with multiple sclerosis.

Up Front

By Douglas G. Franklin
MSAA President and CEO

The first half of 2006 is proving to be extremely busy for MSAA and other MS organizations. Many of us have joined together to advocate for important issues affecting individuals with MS.

The MS community is well aware of the highly publicized debate over whether or not Tysabri® (natalizumab) should return to the marketplace. In early March, a Food and Drug Administration (FDA) Advisory Committee Meeting was held to discuss Tysabri's effectiveness versus the potential for serious adverse events. The Committee ultimately decided that the benefits of this drug outweigh the risks, recommending its return to the marketplace for treating individuals with the relapsing-remitting form of MS.

I represented MSAA at the meeting and advocated for the safety measures recommended by the FDA's Advisory Committee. While safety must be a primary consideration, MSAA enthusiastically supports the development of new medications to treat MS.

March was also MS Awareness Month, which brought together a synergy of effort among the different MS organizations with the goal of working together to benefit the entire MS community. Also in March, MSAA joined with the other MS organizations to advocate for greatly needed funds to be made available for MS research through the National Institutes of Health (NIH).

I am pleased MSAA participated in the NMSS's 15th Annual MS Public Policy Conference held in Washington, DC. This important event is highlighted by "MS Day on the Hill," where attendees visit Congress members on behalf of people with MS.

Once again, MSAA is playing an active role in two important annual medical conferences: the American Academy of Neurology (AAN)'s Annual Meeting held in early April, and the Consortium of MS Centers (CMSC)'s Annual Meeting held in early June. MSAA has a booth and staff at both conferences, giving MSAA representatives an opportunity to interact with a variety of MS specialists.

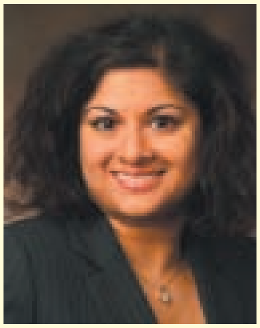
I am proud to announce that MSAA had a poster accepted for presentation at the CMSC Annual Meeting. The poster details the final analysis of MSAA's Needs Assessment Survey.

MSAA, in conjunction with the MS Foundation and the Consortium of Multiple Sclerosis Centers (CMSC), will present a workshop at the CMSC meeting. The workshop is titled, "MS Coalition Resources - A Hands-on Approach" and will define the programs and resources available through the MS Coalition.

I am truly pleased to see MSAA's work expand even further to encompass matters of national importance – including advocacy for drug safety, advocacy for the approval of new treatments, and advocacy for MS research funding. I look forward to the new challenges and many achievements that await us as we work to fulfill our urgent mission. ◆

Douglas G. Franklin joined MSAA as President & Chief Executive Officer in 1999 and has strategically guided its national outreach and corporate partnership support to unprecedented levels. Mr. Franklin is a former national trainer for the Drucker Foundation and is an internationally published expert in the field of social marketing who holds degrees from four universities. He currently serves on the national board of the Key Philanthropic Organizations Committee of the American Society of Association Executives and is a member of the Executive Committee of Health First – America's Charities Board in Washington, DC.

Meet MSAA Board Member Ila Bhatnagar



Ila Bhatnagar is a lawyer in Westmont, New Jersey and has been a member of MSAA's Board of Directors since the fall of 2003. Ila became involved with MSAA through an event that paired lawyers of the Camden County Bar Association with nonprofit organizations in the Camden County, New Jersey area (where MSAA's national headquarters is located). Ila, who was one of the co-chairs of the event, invited MSAA to attend. After speaking with MSAA's President and CEO Doug Franklin and later meeting Bob Rapp, MSAA's vice president for programs and evaluation, Ila thought MSAA would be a great fit for her.

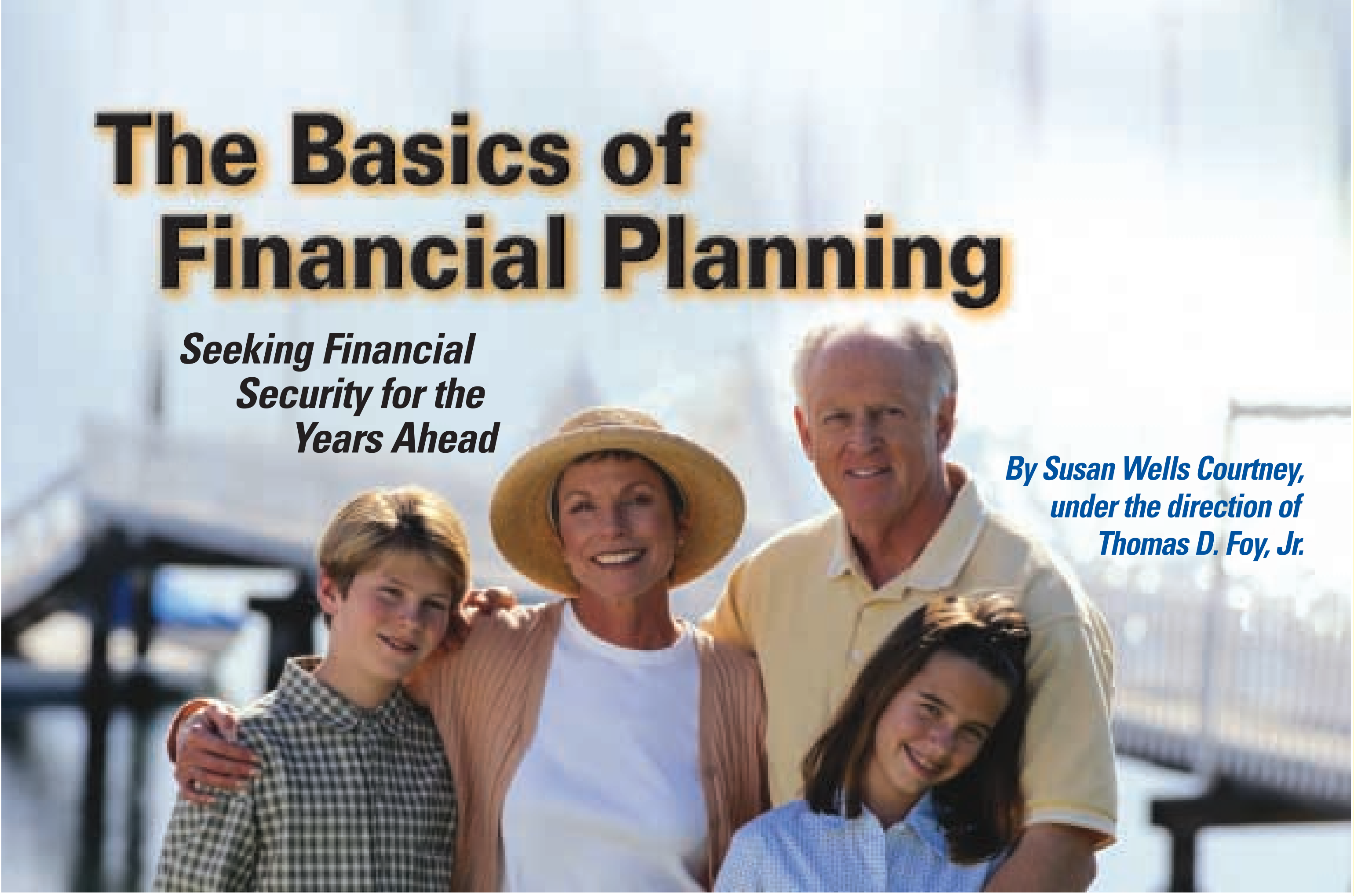
"When I learned about what MSAA does, their mission as an organization, and how they directly work with people in the MS community, I was drawn to them," Ila states. "My specialty as a lawyer is in labor and employment law, which puts me in constant contact with individuals who have disabilities. This experience enables me to better understand the needs of the MS community. I enjoy helping people and MSAA gives me the opportunity to do that."

Since joining MSAA's Board, Ila has seen tremendous growth and numerous achievements, but an event held last May has had the greatest impact. "The one event that stands out in my mind, which best illustrates the growth MSAA has experienced, is the 35th Anniversary Gala," Ila explains. "That event was a great example of everything that MSAA has done over the years – including the advancement of corporate relationships, fundraising, public education events, and the different programs and services – all coming together in one evening."

Through Ila's eyes, the future looks bright for MSAA. "Our organization is in a very positive position for serving the MS community," says Ila. "Using the results of MSAA's Needs Assessment Survey, our organization will be able to directly serve the MS population better and in a more focused manner."

Ila is a native of Lynchburg, Virginia, who now resides in Cherry Hill, New Jersey. She currently serves as chair of the Nominating Committee with MSAA's Board of Directors.

— Amanda Bednar



The Basics of Financial Planning

Seeking Financial Security for the Years Ahead

By Susan Wells Courtney, under the direction of Thomas D. Foy, Jr.

Attaining financial security is a goal that everyone shares. This goal is particularly important for families whose financial obligations include caring for one or more members who are unable to work, and who may be sick or disabled. Having adequate funds available, as well as money held in a Trust with very specific instructions, are just two of several strategies that can help to ensure financial protection and security for your family in the years ahead.

Achieving such a goal, however, requires important decisions, sound investments, and informed planning for the future. Insurance, investments, Trusts, and Wills have become far more complicated than just a generation ago, when our parents were planning for their own futures.

Legal battles and the resultant changes in government laws over the years have led to the need for specific wording in all financial and health-related documents. New laws have added many restrictions. Without such important documents in place, you and your family may not necessarily have the opportunity to decide how one will be cared for, how the money will be distributed, and who will represent a family member if he or she cannot make decisions on his or her own.

According to Thomas D. Foy, Jr. of Foy Financial Services in Mount Laurel, New Jersey, specific language within a document is crucial for how things will be handled when the time comes to put these plans into action. While the expert MSAA consulted for the cover story, "Planning for the Future" (appearing in MSAA's Fall 2005 issue of *The Motivator*), holds the opinion that most legal documents may be completed using standard forms without a lawyer, Mr. Foy strongly defends the need for a lawyer when creating documents such as Wills and Trusts. He also encourages seeking professional help when purchasing insurance and making investment decisions, all of which can have an enormous impact on a family's financial future and healthcare choices.

What is the advantage of professional input? According to Mr. Foy, "Specific language is needed to follow HIPAA (Health Insurance Portability and Accountability Act) laws, which became effective in 1996. The legal forms found online probably do not cover all of the issues. Even with a Durable Power of Attorney, you need to have specific language to allow doctors to discuss personal information with the selected individual; otherwise, such forms are useless."

While these two schools of thought may appear contradictory, MSAA does not support either opinion (whether to seek legal advice or not); but rather presents both arguments so readers may choose for themselves. Readers may also find a small amount of overlap between the two articles – as both talk about Durable Power of Attorney, Living Wills, and Wills – yet overall, this article focuses on the financial aspects, while the previous article focused more on the medical considerations. Readers who would like to see the previous article from the Fall 2005 issue of *The Motivator* may either visit MSAA's website at **www.msaa.com**, select "publications" followed by "*The Motivator*," or they may request a copy by calling MSAA at **(800) 532-7667**.

This article has been written under the professional guidance of Mr. Foy. As an experienced financial advisor, he has seen first-hand the advantages of planning for one's future with the help of informed legal and financial experts. He has also seen the pitfalls of handling such plans improperly, as well as not having any plans in place. Some of the definitions given for the various documents and financial terms were found on **Investorwords.com** – an internet financial glossary.

The Basics, Part I: Income Replacement Strategies, Medical Insurance, and Estate Documents

The basics of any financial plan include income replacement strategies, adequate medical insurance coverage, carefully worded estate documents, and investment planning. The importance of having these plans, documents, and savings in place cannot be understated. These four areas of financial planning will protect and support you and your loved ones when employment and/or health situations change.

Income replacement strategies, medical insurance, and estate documents are described in this first section on the basics

of financial planning. In the following section (part II), an overview of investment planning is provided.

Income Replacement Strategies

The following four types of insurance plans provide income when someone becomes sick or hurt and is unable to work, or when this person dies. If you are eligible for these different types of insurance, having adequate coverage in these four areas will ensure that you and your family receive the necessary financial support when an income-earner in the household is no longer able to work. These include:

- Disability insurance
- Long-term care insurance
- Life insurance
- Critical illness insurance (new)

The latter type of insurance, "critical illness insurance," is new and is quickly gaining popularity. This works by paying a lump sum to the policy holder if and when he or she is diagnosed with an illness that is listed as one of several predetermined "critical illnesses" (as specified in the policy). This provides the policy holder with a large amount of money in one payment, which can be used to take care of extra medical bills, as well as household and family expenses while unable to work.

Medical Insurance

Whenever possible, having adequate medical insurance coverage in place for each member of the family will not only allow for adequate medical care, but will also protect the family's financial security. Whether being treated for a medical condition, long-term illness, or an unexpected injury, medical bills can add up fast and quickly deplete a family's savings.

Opportunities for medical insurance coverage vary between the states. New Jersey has a "no pre-existing conditions" clause, so no one may be excluded due to a condition when starting with a new policy. While this means higher premiums because the insurance companies are forced to cover existing conditions, it also means that you won't be left without coverage should you or a family member encounter a health problem while making a change with a policy.

Estate Documents

A Durable Power of Attorney, Advanced Medical Directive (Living Will), Wills, and Trusts are all different types of estate documents. According to Mr. Foy, "Today, every individual needs to have at least a Durable Power of Attorney, a Living Will, and a Will, all in place and up-to-date. These documents are crucial to your future as well as that of your family."

Mr. Foy continues, "I also strongly recommend that individuals seek the advice of a legal professional when creating these documents. You can't afford not to seek professional advice, especially in today's highly scrutinized legal environment. If these documents are not worded correctly, you cannot be guaranteed that healthcare and financial instructions will be carried out according to your wishes. Additionally, government programs and medical assistance may be affected for a loved one if the money in a Will or Trust is not handled correctly."

A Durable Power of Attorney and a Living Will are examples of "living documents," which means that they are in effect while one is still living; after death, these are no longer active. Wills take over after one dies; and the different types of Trusts may be active during one's lifetime as well as afterward. To follow is some general information about different types of estate documents.

Durable Power of Attorney (DPOA): This gives someone else the authority to act on your behalf and make decisions for you. It includes the ability to make medical decisions ("durable" adds the medical capacity). This document needs to be worded so that all rights are passed along should you become ill or injured and unable to make and communicate your own decisions. A good idea is to prepare this document in multiples, as you may need to surrender copies to the different professionals and/or institutions involved. Most people typically name a significant other and their children as choices for DPOA.

Living Will: This document is used to dictate how to be cared for in your final days. For example, it may include which life-prolonging procedures you may or may not choose to have, such as tube feeding or a respirator. Among other points, it also may state your preference as to where you would like to spend your final days (in a medical facility or at home).

Advanced Medical Directive: Also known as a "Healthcare Power," this document combines a DPOA with a Living Will – either in one document or in two separate ones.

Will: Also known as a "Testament," a Will takes over after death and explains how one's property is distributed. The contents of a Will become public information, accessible to anyone after you die. A Will can also leave everything to a Living Trust, which has certain advantages, including confidentiality, even after you are gone.

Trust: This is a legal arrangement in which an individual (the trustor) gives legal control of property to a person or institute (the trustee), for the benefit of the trust's beneficiaries – who will ultimately receive the property in the trust. A trustor is the individual who sets up a trust, also known as the grantor. The trustee is an individual or organization which holds or manages and invests assets for the benefit of another, often with the legal authority and duty to make decisions regarding financial matters.

As an addition to these documents, individuals may find that they have a need for other types of supporting documents. These may include a Living Trust, a Special Needs Trust, or a Testamentary Trust.

Living Trust: This Trust may be a substitute for a Will, but is frequently an entity within the Will, giving instructions that could replace all the other documents; it is perpetual and private. You can have the Will (which is public information) leave everything to the Living Trust (which remains confidential).

Special Needs Trust: This takes care of the special needs of someone who may be physically and/or mentally impaired. This trust allows someone to be creative within the Will or Trust, but may also be done separately. The trustor who creates the Special Needs Trust can distribute funds as needed before his or her death. Afterward, the appointed trustee or committee of trustees takes over how the funds are managed. Sometimes a life insurance policy will be used as a funding vehicle for a Special Needs Trust (so that after the trustor has died, his or her life insurance benefits are added into the Trust).

A carefully structured and adequately funded Trust can ensure that a spouse, child, or other family members with special needs are cared for throughout their years, even after the person supporting them is no longer living. Some individuals set-up a charity that may continue after the beneficiaries have also passed away.

Mr. Foy notes, "Any family who cares for a loved one with special needs should seriously consider seeking legal advice to create a Special Needs Trust. It should include language focused on the needs of the family member with physical or mental limitations. When drafted by a qualified attorney, the language should be specific enough to maximize state and federal benefits."

Testamentary Trust: This is a Trust that is created within a Will and it does not take effect until the trustor's death. Someone may want to set-up a

Testamentary Trust when specific instructions are needed for how the funds and/or property are to be distributed. A series of instructions lists specific conditions for the beneficiary.

For instance, a Testamentary Trust may be advisable when the beneficiary is under 18 and you are concerned about the responsibility of the child; when the beneficiary is a "spendthrift;" or if the beneficiary may be facing financial problems – such as bankruptcy or divorce. This type of Trust can include "spendthrift language" to provide a level of liability, creditor, and bankruptcy protection.

Mr. Foy explains, "The funds are not easily accessible and this Trust protects the beneficiary from his or her own poor money management, as well as losing money to an ex-spouse during a divorce. A trustee has full power of discretion at the time of legal trouble, having the authority not to disperse any funding at that particular time. In order for this type of Trust to work in this capacity, it must be worded correctly by a lawyer."

The Basics, Part II: Investment Planning

The first advice given by Mr. Foy is to assume that the government won't provide assistance. To be safe, he recommends that a person assumes complete and total responsibility, not depending on any family entitlements. The best way to ensure one's future financially is to save through the following two methods:

- Maximize saving through one's employer, using a retirement plan such as a 401K.
- Create a portfolio of investments – whether for a retirement fund or other accumulated assets. Individuals may wish to seek investment advice to help determine their tolerance for risk and the appropriate investment selection designed to meet their identified investment goals.

For example, young families may be more growth oriented with their financial investments (high risk, high potential), and may choose to purchase company stocks. When people purchase mutual funds, they are investing in company stocks, but they reduce some of their risk because this includes stocks in several companies – so one's success does not depend on the performance of a single company.

Older families, whose objective may be focused on conserving the principle of present investments, also known as "preservation of capital," may stay with more conservative, less vulnerable investments (low-risk, consistent potential). Examples of such investments include cash equivalents (bank accounts, Certificates of Deposit) and Money Market Funds.

Opportunities are available for individuals who feel compelled to invest on their own, however, if someone has resources for investment and qualifies, then he or she may be well advised to seek profes-

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sional advice. An excellent "how-to" guide on investing is a book by Peter Navarro titled, *If It's Raining in Brazil, Buy Starbucks* (published by McGraw-Hill Companies; first edition, 2004).

Mr. Foy points out, "Various financial publications, such as *Money Magazine*, *Fortune*, *Wall Street Journal*, and *Barron's*, may be recommended as resources for individuals to learn terminology and to find out about some general investing tips, but newcomers need to be skeptical of financial advice within these types of publications. Advice should be taken with a grain of salt, as financial editors are not the same as financial planners. Additionally, some may find that the financial advice in certain publications relates directly to the advertisers within the magazine."

To follow are various types of investments, beginning with the most conservative, having the least risk and lowest potential for a high rate of return. As the list continues, it moves onto the least conservative investments, which have the greatest risk but also the best potential for a high rate of return.

MORE CONSERVATIVE INVESTMENTS WITH LESS RISK…

Cash Equivalents:

- Savings accounts
- Checking accounts
- Bank Certificates of Deposit (CDs)

Sometimes cash equivalents are insured by the FDIC. Most investments in general are not insured, because little money can be made if insured. These three types of investments are all handled through a bank.

According to Investorwords.com, a Certificate of Deposit is a short or medium-term, interest-bearing, FDIC-insured debt instrument offered by banks as well as savings and loans. CDs offer higher rates of return than most comparable investments, in exchange for tying up invested money for the duration of the certificate's maturity. Money removed before maturity is subject to a penalty. CDs are low-risk, low-return investments, and are also known as "time deposits," because the account holder has agreed to keep the money in the account for a specified amount of time, anywhere from three months to six years.

- Money Market Funds

Money Market Funds are the safest form of mutual funds, although money markets are not insured. Money Market Funds are usually purchased at an investment firm. Investing money in cash equivalents through the bank (savings, checking, or CD) or through Money Market Funds, may not bring a high rate of return, but does provide a good deal of security, knowing that these types of investments carry the least amount of risk.

Investorwords.com defines a Money Market Fund as an open-ended mutual fund which invests only in money markets. These funds invest in short-term (one day to one year) debt obligations such as Treasury bills, Certificates of Deposit, and Commercial Paper (which is an unsecured obligation issued by a corporation or bank to finance its short-term credit needs). The main goal is the preservation of principal, accompanied by modest dividends. The fund's net asset value remains a constant $1.00 per share to simplify accounting, but the interest rate does fluctuate.

Investorwords.com continues by noting that money market funds are very liquid investments, and therefore are often used by financial institutions to store money that is not currently invested. Although money market mutual funds are among the safest types of mutual funds, it still is possible for money market funds to fail, but it is unlikely. In fact, the biggest risk involved in investing in money market funds is the risk that inflation will outpace the funds' returns, thereby eroding the purchasing power of the investor's money.

Bonds

These are "fixed-income investments." If held until maturity, the rate of return is guaranteed, as well as the return of the original investment. Purchasing bonds involves going through a professional such as a broker. Although not recommended, bonds may also be purchased through an internet trading company. Bonds in general have a relatively low risk for loss of investment. Examples of bonds include:

- Municipal bonds (issued by a legislative body)
- Corporate bonds (issued by a privately owned company)
- Government bonds (issued by the United States Treasury Department)

Investorwords.com defines a bond as a debt instrument issued for a period of more than one year with the purpose of raising capital by borrowing. The Federal government, states, cities, corporations, and many other types of institutions sell bonds. Generally, a bond is a promise to repay the principal along with interest (coupons) on a specified date (maturity). Some bonds do not pay interest, but all bonds require a repayment of principal. When an investor buys a bond, he or she becomes a creditor of the issuer, although the buyer does not gain any kind of ownership rights to the issuer.

Bonds are often divided into different categories based on tax status, credit quality, issuer type, maturity, and whether secured or unsecured (and there are several other ways to classify bonds as well). United States Treasury bonds are generally considered the safest unsecured bonds, since the possibility of the Treasury defaulting on payments is almost zero. The yield from a bond is made up of three components: coupon interest, capital gains, and interest on interest (if a bond pays no coupon interest, the only yield will be capital gains).

A riskier bond has to provide a higher payout to compensate for that additional risk. Some bonds are tax-exempt, and these are typically issued by municipal, county or state governments, whose interest payments are not subject to federal income tax, and sometimes also state or local income tax.

LESS CONSERVATIVE INVESTMENTS WITH GREATER RISK…

Mutual Funds

These are a safer way to invest in a corporation. The sole objective is for the portfolio manager to buy, sell, or hold securities (which include stocks and bonds) for all those who are investing. Mutual Funds may be just stocks, or they may include government bonds, real estate, or almost any other investment – even stock in oil futures. The purpose is to be diversified, providing a "basket of securities" for the investors. The portfolio manager oversees the entire "basket" of investments, enabling investors to each purchase a portion of the basket (holding several investments), so separate purchases of individual securities are not needed.

Investorwords.com defines a mutual fund as an open-ended fund operated by an investment company, which raises money from shareholders and invests in a group of assets, in accordance with a stated set of objectives. Mutual funds raise money by selling shares of the fund to the public, much like any other type of company can sell stock in itself to the public. Mutual funds then take the money they receive from the sale of their shares (along with any money made from previous investments) and use it to purchase various investment vehicles, such as stocks, bonds, and money market instruments.

In return for the money they give to the fund when purchasing shares, shareholders receive an equity position in the fund and, in effect, in each of its underlying securities. For most mutual funds, shareholders are free to sell their shares at any time, although the price of a share in a mutual fund will fluctuate daily, depending upon the performance of the securities held by the fund. Benefits of mutual funds include diversification and professional money management. Mutual funds offer choice, liquidity, and convenience, but charge fees and often require a minimum investment.

Mr. Foy notes that some individuals may consider using insurance company annuities as a means of not outliving their income. These serve a valuable function in certain financial plans, but they are highly complicated and can be very expensive. If structured correctly, annuities can hold investments similar to mutual funds. Individuals should not just buy any annuity; they need to use the right one from the right company, so again, Mr. Foy recommends seeking the advice of a professional.

Investorwords.com defines an annuity as a contract sold by an insurance company, designed to provide payments to the holder at specified intervals, usually after retirement. The holder is taxed only when he or she starts taking distributions or if funds from the account are withdrawn.

All annuities are tax-deferred, meaning that the earnings from investments in these accounts grow tax-deferred until withdrawal. Annuity earnings are also tax-deferred so they cannot be withdrawn without penalty until a certain specified age. Fixed annuities guarantee a certain payment amount, while variable annuities do not, but do have the potential for greater returns. Both are relatively safe, low-yielding investments.

Stocks

Stocks are usually purchased through an investment professional. Stocks may be from small companies, or they may be from large companies, which are known as "Blue Chip" stocks.

- Individuals investing in small companies are looking for a total return of investment, known as "capital appreciation."
- Individuals investing in Blue Chip stocks are investing in big companies and are looking to receive periodic dividends.

As described by Investorwords.com, a stock is an instrument that signifies an ownership position (called equity) in a corporation, and represents a claim on its proportional share in the corporation's assets and profits. Ownership in the company is determined by the number of shares a person owns divided by the total number of shares outstanding. For example, if a company has 1000 shares of stock outstanding and a person owns 50 of them, then he or she owns five percent of the company. Most stock also provides voting rights, which give shareholders a proportional vote in certain corporate decisions. Only a certain type of company called a corporation has stock; other types of companies such as sole proprietorships and limited partnerships do not issue stock.

Investing for the Future

Many individuals are on fixed incomes and have little extra cash for investments. Readers should note, however, that even a small amount of money saved or invested each month can add up over the years. "Financial calculators" are available on many financial websites. With these, individuals may look into various levels of investment and rate of return to determine how their financial investments may grow.

Potential Stock Earnings

The amounts shown are potential stock earnings (BTI) at different interest rates and time intervals, beginning with an initial investment of $5,000. The earnings shown include the $5,000 originally invested.

Interest/Time	5 Years	10 Years	20 Years
8 percent	**$ 7,347**	**$ 10,795**	**$ 23,305**
10 percent	**$ 8,053**	**$ 12,969**	**$ 33,637**
12 percent	**$ 8,812**	**$ 15,529**	**$ 48, 231**

For example, if someone is able to find $100 per month (about $25 extra per week) to invest in a low-risk, fixed-interest type of account, and estimate the rate interest to be at two percent, the savings become significant after several years. Before tax and inflation (BTI) factors are figured in, saving $100 monthly at two percent interest will yield more than $13,000 after 10 years, and nearly $30,000 after 20 years. If the interest is at five percent, $100 monthly would grow to nearly $15,500 after 10 years and more than $40,000 after 20 years (BTI).

Of course, bigger investments into stocks can yield even greater profits—provided they perform well. Stocks are high-risk but have the potential for high interest and a strong return on investment.

For someone investing a one-time amount of $5,000 into a stock, the chart below shows how that might potentially grow over the years. In this example, 100 shares of stock were purchased at $50 each (totaling $5,000), and the total earnings are listed BTI.

For More Information

For assistance with insurance options, readers may contact their local insurance agent, or they may also visit insurance company websites on the internet. Readers are cautioned to look into their options and compare costs, benefits, and the reputation of the insurance company before signing for an insurance policy designed to protect you and your family's future. Examples include:

- Metropolitan Life Insurance Company at **www.metlife.com**
- Prudential Insurance Company of America at **www.prudential.com**

Regarding investments, Mr. Foy points out that many Mutual Fund companies have websites that provide a wealth of information. Often, these resources offer general investing information which is not necessarily designed to encourage selling their own products. Examples include:

- T. Rowe Price at **www.troweprice.com**
- Fidelity at **www.fidelity.com**
- Vanguard at **www.vanguard.com**

Other investment resources include Dow Jones at **www.dowjones.com** and MarketWatch from Dow Jones at **www.marketwatch.com**. Infoplease® offers a listing of personal financial websites which may be found at **www.infoplease.com/ipa/A0001507.html**.

Readers may also consult the Foy Financial Services website at **www.foyfinancialservices.com** to learn more about personal finance and investments. Please note, however, that this agency, headed by Thomas D. Foy, Jr., is located in New Jersey. State securities laws require that your investment professional be registered in the state in which you are a resident. In order to meet this requirement, you must select the state where you reside from a drop-down menu before you may enter this site. If Mr. Foy is registered in that state, you may enter the site. Those who select a state in which Mr. Foy is not registered, will not be able to enter the site.

In Conclusion

Many readers of *The Motivator* may already be fully insured – to provide income replacement and medical coverage; they may also have all of their estate documents in place and up-to-date; and lastly, they may have their investment planning arranged to meet their long-term financial goals. For this portion of our readers, we hope that this article was a reminder to make sure that everything is current and able to meet all of your family's needs.

For those individuals who may not have everything in place, this article was meant to stress the importance of long-term financial planning. It should also serve as a guide to inform you of what is needed for long-term security, and to direct you to the different resources for additional information and assistance. This article is for informational purposes only. MSAA and Foy Financial Services are not responsible for any legal and/or financial decisions made by our readers.

MSAA and its staff would like to thank Thomas D. Foy, Jr. for generously donating his time to the writing of this article. We hope that many of our readers may benefit from his valuable knowledge and expertise. ◆

Genealogy:

A Rewarding Hobby With Easy Access

by Loretta Evans, AG

While author Loretta Evans, AG, researched her family's history, she discovered this photo (above) of her great-great grandmother Eliza Cusworth Staker, shown here with two of her daughters and a granddaughter. Shown at left is the first photo that Loretta uncovered while learning about her family's history. This is her Great Grand Aunt Cora Steward. After finding the photo, Loretta was hooked on genealogy.

Family history is one of the fastest growing hobbies in the United States. More and more people have discovered the fun of tracing their ancestors. With the advent of the internet, it has become easier than ever before.

Genealogy is a versatile hobby. One's family history may be recorded with a simple pen and paper, or it can involve expensive computer equipment. People with MS are discovering that genealogy is fun and flexible enough to allow for when they are having both good and bad days.

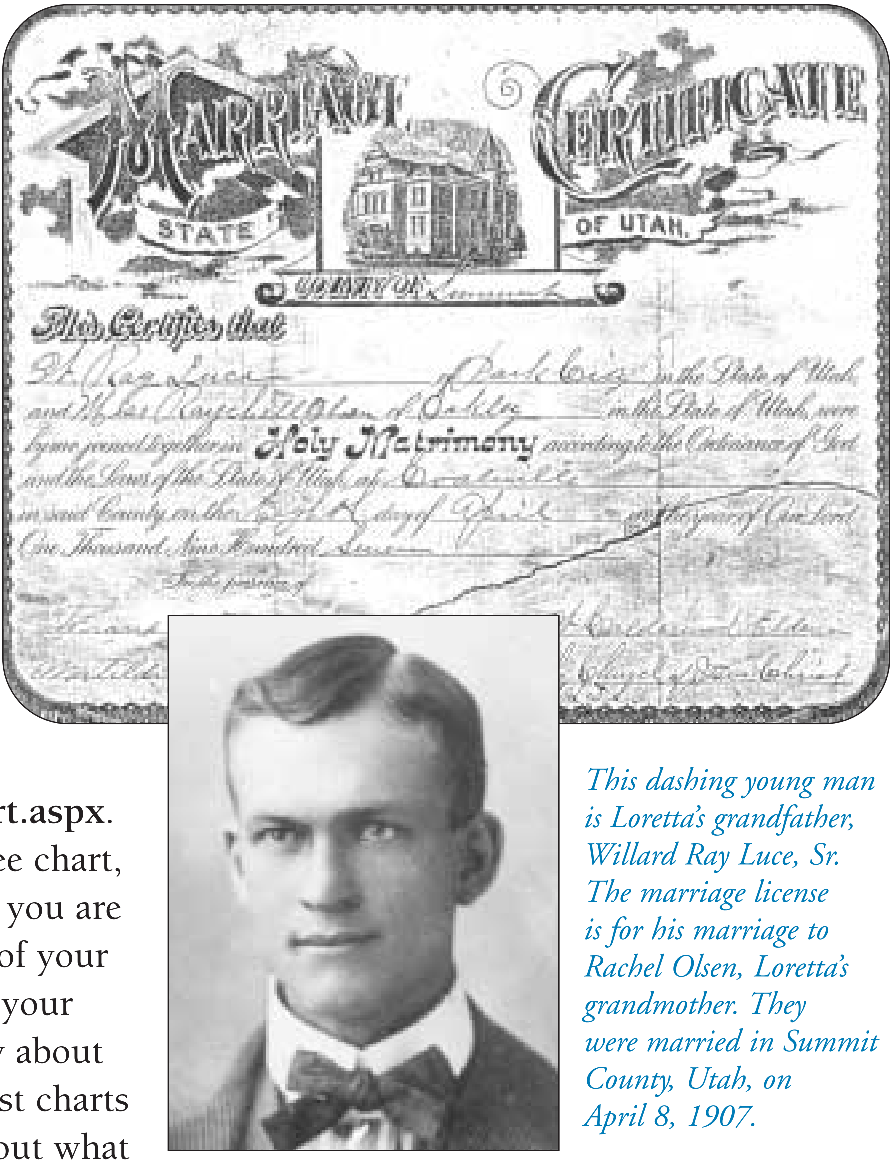
I got started doing family history research back when I was in college. I had been reading my great grandmother's obituary in a faded scrapbook. It said that she was survived by a brother and a sister. I realized that I had information on three of her brothers, but I had no record of a sister. Suddenly, I had to find that missing sister. I had found my great grandmother and her brothers in the 1860 census in a small town in Ohio. No sister was mentioned. I got the roll of microfilm for the same town in the 1870 census. At that time there was no index, so I started with the first family recorded by the census taker. After reviewing records of dozens and dozens of families, I finally found the right people. The ink had faded, but I could make out a six-year-old sister named Cora. Later I found a family photograph of a large lady in a big hat, labeled "Aunt Cora." Finding Cora hooked me on genealogy.

Since my diagnosis with MS, I realized that genealogy was perfect for me. On days when I felt good, I could search the web, write letters, or visit a Family History Center. On days when fatigue took over, these people – now deceased – could wait until my energy returned.

Doing family history research is like a

detective looking for a missing person. Working from known information and making educated guesses has led me to public records that have helped fill in the gaps in my pedigree.

People just getting started should begin with some blank forms. Pedigree charts show one person's direct ancestors. Family group sheets record all the children in each family. There are several places on the internet where blank forms can be downloaded. One place is at Ancestry.com: **www.ancestry.com/charts/ancchart.aspx**.



MARRIAGE CERTIFICATE

STATE OF UTAH.

COUNTY OF [illegible]

This Certifies that

[illegible] of [illegible] in the State of Utah,
and [illegible] of [illegible] in the State of Utah, were
by me joined together in Holy Matrimony according to the Ordinance of God
and the Laws of the State of Utah, at [illegible]
in said County on the [illegible] day of [illegible] in the year of Our Lord
One Thousand Nine Hundred [illegible]

In the presence of

This dashing young man is Loretta's grandfather, Willard Ray Luce, Sr. The marriage license is for his marriage to Rachel Olsen, Loretta's grandmother. They were married in Summit County, Utah, on April 8, 1907.

Start with yourself. On a pedigree chart, record your birth date and place. If you are married, record the date and place of your marriage and birth information for your spouse. Then fill in what you know about your parents and grandparents. Most charts show four or five generations. Fill out what you know from memory, but use a pencil, so you can make corrections if necessary. When recording each woman, use her maiden name if you know it.

Then take one family group sheet. If you are married, create one sheet for you and your spouse. If you have children, record information about them on that same chart. Then fill out another family group sheet showing you as a child. This sheet will include your parents and brothers and sisters. Once again, do the best you can from memory.

If you are able, fill out a form for each set of grandparents, showing your parents as children with your aunts and uncles. By now you probably won't know all the details.

At this point start contacting relatives. You can ask living people to give you dates and places. They may remember details about relatives who have died. Be sure to record who gave you what information.

Then look through documents you own. Do you have any official certificates of birth, marriage, or death? Has someone saved newspaper articles or funeral programs? A trip to a family cemetery may yield additional information.

About this time you may find that

This photo is of the B. F. Larsen family, taken about 1922. Here Loretta's grandparents pose on a porch with their three sons and daughter – who later became Loretta's mother.

typing your information into a computer can help you keep track of all that data. There are a number of excellent programs available. I like the Personal Ancestral File 5.2. The biggest advantage is that it is free and can be downloaded from the internet. Go to **www.familysearch.org**. Click on "Order/Download Products." Then click on "Software Downloads – Free."

For each piece of information missing from your charts, think about what kind of records might contain the missing data. For example, a tombstone could give both birth and death dates. Some headstones even list the names of spouses or parents. The 1930 census could show everyone living with the family the day the census was taken. It will also show their relationship to the head of the household, each person's age, the state or country where they and their parents were born, the occupations of each adult, and even whether the family owned a radio.

Many records have been posted on the internet. Some sites charge money for their services, but many are free. Be aware that not everything on the internet is accurate. If you record data you have found, be sure you record where you found it. If you discover two sources that conflict, you might be able to judge which is the most reliable.

The more you learn about your family, the more you will appreciate them. You will find heroes and black sheep, but most of all, you will find real people. Their struggles will help you appreciate your own. Many of us have various challenges we must face each day while living with MS. Despite these hardships, our ancestors had some challenging moments as well. For instance, you may become fatigued while food shopping, but you probably never had your crops destroyed by grasshoppers; and while travel might be challenging at times, you never put everything you owned into a covered wagon and walked two thousand miles to a new home you had to build yourself.

Delving into your family's past often reveals many interesting facts that could surprise you. You may find that your youngest son looks a lot like your great grandfather. You may discover that an uncle loved to play the violin, just like you do. The more you find about your family, the more you will discover about yourself.

Ten Things You Can Do to Preserve Your Family History

1. Write your own life story. You don't necessarily need to start with your birth and go chronologically. Write about brief memories as they come to you. If you save your memoirs on a computer, you can put each short essay into chronological order at a later time, if you choose to do so. Be sure you save a backup of your computer file on disk or print out a paper copy. Computers have been known to crash at the most inconvenient times.

> *"The more you learn about your family, the more you will appreciate them. You will find heroes and black sheep, but most of all, you will find real people. Their struggles will help you appreciate your own."*

2. Organize and label family photographs. How many people have boxes of snapshots in various places throughout the house? By labeling the pictures and organizing them, the collection will be far more valuable. Be careful to label photographs with a pencil or photo-quality marker. Ball-point pens can leave ridges on the right side of the picture. You may want to organize the pictures into albums. If you do, use acid free materials and label the people in each shot. You may know everyone in your album, but 100 years from now, will your descendants recognize anyone?

3. Transcribe family letters, diaries, or other documents. If you have letters or journals that belonged to your ancestors, you might want to preserve them. One way is to copy them into a computer file, so more family members can enjoy them. Be sure not to "correct" spelling and punctuation. The way the items were originally spelled is part of the charm. The history of your family played a role in the history of the world. A local historical society or university library might also be interested in having a copy.

4. Document family heirlooms. You may own items that belonged to your ancestors. Do any of your relatives know the stories behind the treasures? Take time to photograph each item and to write a brief story about who owned it and why it is important. You can make a file of these stories, either in a binder or on your computer. Keeping an extra copy in your safe-deposit box at the bank is a good idea in case of natural disasters. This file can help your relatives know what items you own are of significance to your family's history.

5. Document your descendants. Do you have birth, marriage, and death information for each of your descendants and their spouses? It wouldn't hurt to have copies of official certificates on file as well. A computer genealogical program can help you organize this data, but paper forms also work well.

6. Update your resume. A resume can be important when job hunting, but it can also be a good source of family history. Do you have a record of each job you have held? How about volunteer work you have done? Do you have a list of awards you have received? Taking time to record milestones as they happen is much easier than recalling them if you should need the information.

7. Interview older family members. Each time someone dies, their memories are no longer available to the rest of us. If you have parents, grandparents, or other elderly relatives, now is a good time to record their memories. Make an appointment and give them some of the questions you would like to ask. You can record the interview with either a tape recorder or a video camera. Be sure that the microphone is close enough that the person's voice is clearly recorded. Be aware of background noises that could interfere with the recording, such as a barking dog or a ticking clock. Usually about an hour is long enough. If you have more questions, plan a second visit. Be sure to give the person a copy of your interview. With his or her permission, you can distribute the tape to other family members. Local libraries and historical societies might like a copy as well.

Shown here is Loretta's great-grandfather's sister. Married twice, her full name was Emily Luse Fletcher Rogers.

8. Collect data on your ancestors. Using a blank paper form or a computer genealogical program, record birth, marriage, and death dates and places for your ancestors as far back as you can remember. Then visit with other family members to see if they have additional information. Write down where you got the information. Did Aunt Mary tell you her birth date, or did you get it from Cousin Martha? Do you have any documents, such as certificates, funeral programs, or newspaper clippings? If so, record the information and the source.

9. Visit a Family History Center. Family History Centers are found throughout the world. They are sponsored by the Church of Jesus Christ of Latter-day Saints, but their services are free and open to the public. You do not need to be a member of that church to use the facilities. You can find the address and contact information for a center by going to **www.familysearch.org/Eng/Library/FHC/frameset_fhc.asp** and typing your location. Trained people will be there to help you get started.

10. Take a class on genealogy. Local genealogical societies and Family History Centers often offer classes on genealogical research. In addition, there are several places on the internet that offer online classes. Some of the best beginning courses are "Finding Your Ancestors" (#FHGEN 68) and "Introduction to Family History Research" (#FHGEN 70). They are available through Brigham Young University, and they are free of charge.

MSAA Needs Volunteers!

Volunteering assignments include:

- Public Education Ambassadors
- Support Group Leaders
- Professional Volunteers (including lawyers, occupational and physical therapists)
- Independent Volunteer Fundraisers
- Resource Detectives

Please contact Malcolm Friend at MSAA
Phone: (800) 532-7667, ext. 8
Email: volunteering@msaa.com
Website: www.msaa.com/volunteer.html

(When sending an email, please include areas of interest for volunteer work and any contact information.)

You can find more by going to: **ce.byu.edu/is/site/courses/freecourses.cfm.** BYU also offers free classes on doing original research in France, Germany, and Scandinavia. The National Genealogical Society provides an excellent series of online classes as well. For more information, go to **www.ngsgenealogy.org/edu.cfm**.

About the Author

Loretta Evans of Idaho Falls, Idaho, is an Accredited Genealogist^{CM} researcher specializing in Midwestern United States Research.

She is a freelance writer and lecturer on genealogical topics. She has been reading microfilm, wandering cemeteries, and fostering a love/hate relationship with her computer for more than 30 years. When she is not doing genealogy, Loretta likes to cook, read, and work in her garden. She has a husband, five grown children, and a dog. They all love her despite her fascination with people who are no longer living.

Loretta contributed this two-part article for MSAA's feature article in this issue of *The Motivator*. She also contributed a second article for a new column appearing on page 48 of this issue. Many thanks go to Loretta for her generosity. ◆

Ask the Doctor

By Dr. Jack Burks
Vice President &
Chief Medical Officer for MSAA


Dr. Jack Burks

Q: I am 55 years old and was diagnosed with MS five years ago. The warmer temperatures in the southeast this winter have caused much perspiration around my head and neck. Since last year, the sweat pours down my head and off the tips of my hair – even when the temperature is 45 degrees outside – and is very embarrassing. I've stopped going out with friends because I start sweating as soon as I get involved with any activity. Can you tell me why this is happening and do you know of any treatment that can help?

A: Sweating is controlled by the autonomic nervous system (ANS). The ANS also controls heart rate and breathing rate. One of the most common symptoms of MS patients are cold, white hands, or the bluish appearance of skin – both related to the ANS. Fortunately, profuse sweating is not commonly caused by MS, therefore, I would look for other causes such as an over-active thyroid. You should ask your physician about other potential causes of excessive sweating. Treatment will depend on the underlying cause. If severe enough, medications or nerve blocks may be tried.

Q: I have had Devic's disease for four years and was wondering what lies ahead in my future.

A: Devic's disease is an inflammatory disease, primarily of the optic nerve (going to the eye), and the spinal cord. It may flare-up only a few times or it may flare-up many times over several years, making it difficult to distinguish from MS. Devic's disease may cause more disability than MS, but there is variability in the disease pattern. More information is available on the Mayo Clinic's website at **www.mayoclinic.org/devics-disease/about-devics.html**.

The Mayo Clinic has developed a new antibody test which may help differentiate Devic's disease from MS. Treatment options are available if necessary, and recent advances in our knowledge of Devic's disease should lead to even better treatments in the future. Steroids, plasmaphoresis, IV gamma globulin, and anti-cancer drugs are all potential treatments at this time.

Q: My daughter has had MS for six years. She gives herself a weekly injection and hasn't had any flare-ups since her diagnosis, although she has cognitive issues and her balance is not good. Her symptoms don't appear to be getting any worse, and she actually seems to be getting better since her divorce (happier and working part time). She goes annually for checkups at the Cleveland Clinic. I have two questions: (1) does traveling by plane have any negative effects on someone with MS; and (2) do you think that her MS might have stabilized?

A: (1) No data suggest that plane trips have any negative effects on individuals with MS. Most of the people I see who have MS fly whenever needed without any concern for their MS.

(2) Whether or not your daughter's MS has stabilized is a question best asked to her physician. While I'm pleased that she is feeling better, I'm concerned with her having balance and cognitive problems. Are they worse now than a year or two ago? If so, she may be developing the progressive form of MS, which may require a re-evaluation of her medications.

Q: **I have been on an MS drug since 1997 and recently noticed that I sometimes get a quarter-sized black and blue spot where I give myself the weekly injection. I've talked to others on the same medication and this happens to them also. What causes this and is there anything I can do to prevent it?**

A: I assume your weekly injection is in the muscle (using Avonex). My experience is that it is unusual to have skin reactions with Avonex. I believe that the most common reason for a skin reaction to an interferon is related to medication being on the outside of the needle.

Some patients squirt the medication out of the needle to "get rid of the air bubbles" before injecting. Unfortunately, this allows the medication to coat the outside of the needle, which can irritate the skin. My recommendation is to consult with Avonex's nursing support system to give assistance with the injection technique. The nurse at your doctor's office may also be able to provide this service. To contact the support staff at Biogen (the makers of Avonex), individuals may call **(800) 456-2255** or visit **www.avonex.com**.

Regarding the issue of air bubbles in an injection, I suggest that you ask your doctor or nurse about how you may avoid injecting a large amount of air into an artery when giving an intramuscular injection. And, if you do get medication on the needle, I recommend that you change the needle before injecting. Air bubbles are not a problem with subcutaneous injections (these injections are given just under the skin using tiny needles).

Q: **Two readers ask about visual problems…**

(1) My sister has secondary-progressive MS and has been experiencing double vision for the past year. Her optometrist disagrees that she has double vision and would not prescribe prism glasses. My sister says that her vision is "jumping all around." The neurologist says she has bilateral intranuclear opthalmoplegia (INO) and there is nothing she can do. Do you know of any treatment that can help?

(2) My husband has MS and is experiencing a profound visual problem called "oscillopsia," causing chaotic eye movements and bouncing vision. His neurologist prescribed valium and suggested he see a neuro-ophthalmologist; do you have any recommendations?

A: I recommend that both patients see a neuro-ophthalmologist who specializes in MS. These are difficult issues and require the highest level of MS and ophthalmology expertise. Sometimes people are able to adapt to this “bouncing vision” after several months and the symptom may improve.

Q: My neurologist has told me that hearing is not affected by MS, however, my hearing specialist tells me that my hearing problems are associated with MS and cannot be treated. Can you tell me who is correct?

A: Hearing problems are unusual with MS, however, they can occur. I look for other causes first, before I attribute hearing loss to MS. If hearing problems arise as part of an attack with MS, they could potentially improve with high doses of steroids. When a hearing problem cannot be treated, please note that there are many devices available, such as hearing aids and special phones with increased volume, to help individuals cope with hearing impairment.

Q: My neurologist wants to give me Botox injections to treat weakness in my leg. Is this a commonly used treatment for weakness?

A: Botox injections may be used to treat muscle stiffness (also referred to as “spasticity”), but not for weakness. In fact, one potential side effect of Botox is weakness. I recommend that you discuss this possibility with your doctor before getting any Botox injections.

Leg stiffness often requires large doses of Botox and the stiffness will return after

several months. Therefore, repeated injections may be needed over time. For selected patients, Botox can be very effective, but many insurance companies do not pay for this expensive treatment.

No specific medications are available to treat weakness. I refer MS patients with weakness to a physical therapist (PT) for evaluation and strengthening exercises to help the affected muscles. The surrounding muscles, which may not be affected by the weakness, are also helped through such exercise, and may be able to take over the affected muscles. Please note that leg weakness is associated with an increased risk of falling. A PT can address this issue and possibly recommend an assistive device, such as a cane. ◆

Jack Burks, MD, is a neurologist who specializes in MS. He is vice president & chief medical officer for MSAA, as well as president of the Multiple Sclerosis Alliance. Additionally, Dr. Burks is a clinical professor of medicine in neurology at the University of Nevada School of Medicine in Reno, Nevada, and a member of the Medical Advisory Board of the National MS Society. He has edited two textbooks on MS, and in the 1970s, Dr. Burks established the Rocky Mountain MS Center in Colorado, one of the nation's first comprehensive MS centers.

To Submit Questions to Ask the Doctor…

Many of these questions were submitted by readers. If you have a question that you would like to ask, please submit your question to:

MSAA
Questions for Ask the Doctor
Attn: Andrea Borkowski
706 Haddonfield Road
Cherry Hill, New Jersey 08002

Readers may also send in questions via email to aborkowski@msaa.com. Please be sure to write "Ask the Doctor" in the subject line.

Clinical Trials Resource Center Now on MSAA Website

MSAA's new Clinical Trials Resource Center may be found at **www.msaa.com** and is presented in partnership with Thomson CenterWatch. Through the Clinical Trials Resource Center, website visitors may learn more about clinical research and new medical therapies for treating multiple sclerosis. Topics available include:

- Clinical Research (and the clinical trials process)
- Listing of Multiple Sclerosis Trials
- Listing of Studies from the National Library of Medicine
- Email Notification Service
- FDA Drug Approvals
- Neurology Research Centers
- CenterWatch Research Headlines
- New Medical Therapies (NMT) Trial Results
- Patient Bookstore

Please also visit **www.msaa.com** for information on all of MSAA's programs and services, including regional events and activities in your area. Copies of MSAA publications are available on the site, as well as news updates and other important and useful information for the MS community. ◆

Research News

Initial Trial Results for FTY720 are Encouraging

Data from Phase II studies of FTY720 (fingolimod) for individuals with relapsing-remitting MS (RRMS) show encouraging results at 18 months. FTY720 is an investigational drug for MS that is given orally (by mouth) once per day. Novartis, the company that developed and is testing the drug, presented the data at the American Academy of Neurology's (AAN) Annual Meeting. According to Novartis, the study's two treatment arms (taking 1.25 mg and 5 mg daily) experienced more than a 50 percent reduction in their annualized relapse rate compared to placebo.

These results were initially shown during the first six months of the study, and were maintained through the subsequent 12-month extension (totaling 18 months). Study participants who switched from placebo to one of the treatment arms (receiving FTY720 at either dose) after six months, also experienced the same reduction in relapse rate.

Magnetic Resonance Imaging (MRI) scans were performed in a subgroup of patients. Consistent with what was seen with the MRI scans after six months, the vast majority of these study participants were reported to be free from lesions showing active inflammation after 18 months on the drug.

Adverse events during the first six months of treatment included: first-dose heart rate reduction; increase in blood pressure; alteration in liver function; and mild increase in airway resistance. These did not appear to progress with continued dosing beyond the initial six months. In patients treated for up to 18 months, the most commonly reported adverse events were non-serious infections (colds, influenza) and headache. All participants in the extension study are now on the lower, 1.25 mg dose, since the higher, 5 mg dose, had an increased rate of adverse events, while both doses were equally effective in reducing disease activity.

The drug is believed to work by lowering the number of activated T-cells circulating to the blood stream and central nervous system. This in turn reduces inflammation and myelin damage in the brain and spinal cord. A two-year, Phase III study called "FREEDOMS" (Fingolimod Research Evaluating Effects of Daily Oral therapy in Multiple Sclerosis) will include more than 1,000 participants. The study has begun enrolling in Europe; Novartis is currently discussing Phase III trials in the United States with the FDA.

MBP8298 Shows Promise in Treating Subgroup of MS Patients

MBP8298 is an investigational treatment being studied for safety and effectiveness in a subgroup of individuals with secondary-progressive MS (SPMS). The drug shows potential when used for SPMS patients who possess the HLA-DR2 or HLA-DR4 immune response genes. This "responder group" is believed to comprise up to 75 percent of the

MS population.

Developed and studied by BioMS, MBP8298 is administered intravenously every six months. According to the company's data presented at the AAN's Annual Meeting, this treatment showed a five-year delay of disease progression for individuals with SPMS. Treatment and follow-up of patients from a phase II clinical study demonstrated that those within the responder group (having the HLA-DR2 or HLA-DR4 immune response genes) had a median time to disease progression (worsening) of 78 months (six-and-a-half years) compared to 18 months (one-and-a-half years) for patients who received a placebo. Disease progression was measured according to the Expanded Disability Status Scale (EDSS). These findings were based on the long-term follow-up treatment and assessment of 20 progressive MS patients with the response genes mentioned.

BioMS is presently enrolling approximately 553 individuals with SPMS in Canada, the United Kingdom, and Sweden. The Phase II/III study will evaluate a 500 mg dose of MBP8298 administrated intravenously every six months, compared to a placebo, over a two-year period. The primary clinical endpoint for the trial will be time to progression, as measured by the EDSS. To date, the trial has successfully completed three safety reviews by its independent Data Safety Monitoring Board.

MBP8298 is a synthetic peptide that consists of 17 amino acids, which are linked in a sequence identical to that of a portion of human myelin basic protein (MBP). More

than 26 years of research have gone into this investigational treatment. MS is believed to be an autoimmune disease, caused by an immune attack against normal components of the central nervous system. MBP8298 is a molecular replicate of the site of attack for patients with the HLA haplotypes DR-2 or DR-4. This drug has been designed to work as a decoy for the immune system T-cells which damage the CNS in this subgroup of MS patients.

FDA Advisory Committee Supports Tysabri's Return to Marketplace; Review Period Extended by 90 Days

Following the Food and Drug Administration's (FDA) Peripheral and Central Nervous System Drugs Advisory Committee Meeting on March 7 and 8, 2006, members of the Committee decided that Tysabri's effectiveness outweighs the potential for serious adverse events, recommending its return to the marketplace for treating individuals with the relapsing-remitting form of multiple sclerosis (MS).

Manufactured and marketed by Biogen Idec and Elan Corporation, Tysabri® (natalizumab) is an investigational drug being studied for the treatment of MS. It was given early approval in November 2004, but was voluntarily suspended three months later after progressive multifocal leukoencephalopathy (PML), an often-fatal brain disorder, was confirmed in three patients who had taken the drug.

Although the Advisory Committee's recommendation does not guarantee that Tysabri will be approved, the FDA typically follows the recommendation of its Advisory Committees. According to an FDA spokesperson, a risk-management plan for patients is being planned and a patient registry may also be set-up; additional patient-safety studies will be conducted as well.

Two weeks after the March 2006 Advisory Committee meeting, the FDA posted a statement on the review time for Tysabri. According to the statement, the FDA had extended the regulatory review period up to 90 days, allowing the FDA more time to review the new information supporting the reintroduction of Tysabri for the treatment of MS. The agency hopes to have completed the review of new information before the end of the 90-day extension period.

Serono Submits New Rebif Formulation for FDA Approval

On April 4, 2006, Serono announced that it has submitted an application to the FDA (as well as to the European Medicines Agency) for a new formulation of Rebif® (interferon beta-1a). This drug is presently approved for the treatment of relapsing-remitting MS (RRMS) and is given via subcutaneous injections three times per week.

According to Serono, this new formulation results in a substantial improvement in overall tolerability, including injection site reactions. Additionally, trial data show that the incidence of antibody formation with this new formulation is reduced. Serono plans to present this data at a major medical conference in the second half of this year. ◆

— Susan Wells Courtney

Program Notes

Cooling Kits Now Available

As the summer approaches, the heat and humidity can often cause adverse effects for individuals with MS. Recognizing this, MSAA provides special cooling apparel at no charge to individuals with MS through its national Cooling Distribution Program.

This year, MSAA has revised the program to include five different cooling kits in an attempt to make the selection process easier and more effective for our client members. All kits will include a vest, collar, and set of wrist bands. These three products address the three primary cooling points on the body (torso, neck, and wrists).

Clients eligible for the program will be able to choose one of the five cooling kits that best fit their needs. They may also choose two accessories from a selection of 12. The accessories are additional products to help meet cooling needs, such as a variety of hats, seat pads, and items for your hands and feet.

These products offer a mild cooling effect which allows people to enjoy the outdoors in warm weather. They use three different methods to create a cooling effect.

The first type of cooling is through evaporation. Through evaporative cooling, products are soaked in cool water and towel dried. This activates crystals inside the garment and evaporation lowers the temperature of the product. This type of cooling is not recommended for humid climates.

The second type of cooling uses ice packs that are inserted into the pockets or pouches of the apparel. The ice packs are frozen at 32 degrees and release the maximum amount of cooling energy from a non-therapeutic system.

The third type of cooling involves gel packs. Similar to ice packs, the gel packs are inserted into the pockets or pouches of the apparel, but are cooled to 45 degrees. These products do not offer the same cooling energy as ice packs, but are especially helpful for those who travel and can bring along a portable cooler to recharge the packs (making them cool again).

The Cooling Distribution Program also offers clients the possibility of receiving a cooling therapy system which is used indoors for those with severe heat intolerance. The cooling therapy system uses a pump to circulate cool water through tubes sewn into a vest. This type of cooling attempts to reduce brain and spinal tissue temperature by a small amount and requires a physician’s prescription.

For those interested in applying to the MSAA Cooling Distribution Program, please contact MSAA by calling **(800) 532-7667**. Readers may also download the application forms at **www.msaa.com**. ◆

— Peter Damiri

Strategies to Help with Cognitive Problems

For many years, cognitive issues were not believed to be a symptom of MS. In more recent years, however, researchers and physicians have come to find that roughly half of the MS population will experience some type of change with cognitive functioning. Thankfully, cognitive problems are usually not severe and tend to fluctuate, sometimes worsening when tired, overheated, or under stress.

Frequently individuals with MS who are experiencing cognitive problems find that they simply can't remember things as well as they once did – a problem shared by many with or without MS. They may forget that they put water on the stove to boil, where they left their glasses, or when they have an appointment. Executive function may also be compromised for some individuals, affecting one's judgment and the ability to make appropriate choices. Some may experience an unexpected "lapse" of memory or cognitive functioning, possibly affecting their ability to find the right words, concentrate, or recall what they were talking about.

If you or someone close to you is experiencing cognitive issues – whether mild or severe – seeing a medical professional is an important first step. Often a physician will refer someone to a neuropsychologist, who can make an evaluation through various cognitive tests – and make sure that something other than MS is not involved. After an assessment has been made, individuals having cognitive problems may employ several strategies to help them better cope with the changes they may be experiencing.

In the book, *Multiple Sclerosis: A Self-Care Guide to Wellness*, second edition (edited by Nancy J. Holland, EDD, RN, MSCN and June Halper, MSCN, ANP, FAAN; published by The Paralyzed Veterans of America and Demos Medical Publishing, LLC, 2005), one section is devoted to "Coping with Cognitive Changes." It lists the different types of cognitive functions that may be affected by MS, which include difficulties with the following:

- Memory
- Abstract reasoning
- Information processing
- Word-finding
- Visual and spatial organization (such as driving or reading a map)
- Ability to shift between tasks
- Attention and concentration
- Organization and execution of complex sequences

To enhance one's ability to concentrate, this book recommends: identifying (and avoiding) distractions; establishing quiet time; determining a time when you are at your best and using that time to perform more complex tasks; learning energy-saving and pacing strategies; finding out how long your attention span can last and taking breaks while working when you know that your attention is no longer sharp; and breaking tasks down into sections so you don't have to complete a task all at once. Puzzles, meditation, and reading can also help enhance your ability to concentrate.

If having trouble processing information, ask those around you to not speak as quickly, allowing you time to assimilate the information. By letting family and friends know what is going on, they will be able to help you to cope with any cognitive challenges you may be experiencing.

If having trouble finding a certain word, the best idea is to wait and let the word come to you later. You may also try to talk more slowly, allowing yourself extra time to process information. Additionally, if you study and expand your vocabulary, you may have synonyms at your disposal to substitute for the words you can't find.

Other important strategies include getting organized. This can help substitute for any lapses in memory. For instance, use a journal and/or a calendar to help keep track of things you need to remember and appointments you need to keep. Use checklists for shopping and other tasks. Select a central place in your home to keep things that are easily lost—such as glasses and keys—to help avoid the frustration and wasted energy of searching for lost items.

Another very helpful resource is Shelley Peterman Schwarz's new edition of her book, *Multiple Sclerosis: 300 Tips for Making Life Easier* (published by Demos Medical Publishing, LLC, 2005). In this second edition, Ms. Schwarz presents tips that cover all the basics: from issues around the home and managing meals, to taking care of yourself, handling medical issues, and even travel. The book also includes a section on improving memory and concentration. Among others, some of her tips include:

- Write reminders (self-adhering Post-it® notes may be helpful) and put them where easily seen.
- Keep a small spiral notebook with a small pen or pencil with you to jot down things you need to remember.
- Use a gardener's apron while at home; it has big pockets and can carry the small notebook and other items (glasses, portable phone, etc.), allowing you to work "hands-free" around the house and conserve energy by not having to take extra steps to retrieve things.
- If you like gadgets, an electronic organizer (also known as a personal data assistant or PDA) can keep addresses and phone numbers, appointments, notes, to-do lists, etc.
- Your computer, pager, or cell phone can be programmed to "beep" when you need a reminder for taking medicine, performing a task, or attending a meeting.
- If you have trouble remembering if you have done a task, remind yourself by speaking out loud; for example, when leaving the house, say, "I'm locking the door," out loud, and this may help your memory.
- When running errands, plan your route in advance and write down the stops you need to make in sequence; this will help you to remember everything you need to do, saving time and energy.
- If you are out and need to remember something to do when you return home, call and leave yourself a message on your answering machine.

Another excellent resource is a book which focuses on the experiences one goes through with changes in cognitive function. Titled *Facing the Cognitive Challenges of Multiple Sclerosis* (written by Jeffrey N. Gingold and published by Demos Medical Publishing, LLC, 2006), this book tells how the author came to find he had MS, and how he tried to conceal and cope with cognitive issues as well as other MS symptoms – all while working as a lawyer and continuing his strong roles as a devoted father and husband.

While telling his story, Mr. Gingold talks first-hand about the thoughts that went through his mind as he would unexpectedly encounter a lapse in memory, an inability to recall words, or find himself lost on a familiar road. He includes details about the other symptoms he was experiencing, consulting doctors, going through the different tests involved with MS, and taking medication.

When taking a different path, his advice includes: if retiring from a career, choose to do something different that is challenging and interesting; don't think you are without options – many choices are available; keep your mind active by reading books, keeping a diary, and doing crossword puzzles (challenge your mind); sometimes you need to say "no" to requests from others to maintain clear thinking; ask for clarification, reminders, and direction when in a confusing situation; pause, relax and breathe calmly when having a temporary lapse in thinking; limit visual distractions and remove clutter from your home; keep lists of daily responsibilities and activities.

The story the author tells is honest, intelligent, and often humorous. Throughout the writing he notes facts about MS and strategies for acknowledging and coping with the cognitive changes MS may impose. Readers with MS may relate to and learn from his experiences, while readers without MS may better understand the effects of cognitive issues and how one feels to suddenly encounter these perplexing symptoms.

Multiple Sclerosis: A Self-Care Guide to Wellness (MSAA book # 264) is available through MSAA's Lending Library and is highlighted on page 51 of this issue. *Facing the Cognitive Challenges of Multiple Sclerosis* (MSAA book # 158), as well as the newest edition of *Multiple Sclerosis: 300 Tips for Making Life Easier* (MSAA book # 60), are expected to be available through MSAA's Lending Library by the time this issue is received by our readers; please see page 51 for more information. All three of these new books may also be purchased through Amazon (at **www.amazon.com**) or Barnes & Noble (at **www.bn.com**); Barnes & Noble may also be contacted by calling (800) 843-2665. ◆

Due to a clerical error in our last issue, MBP8298 was mistakenly listed as an oral drug under investigation. This drug is given intravenously (please see pages 38 to 40 of this issue). We apologize for the error.

In Search of My Mother's Garden

By Diana M. Amadeo, Volunteer Contributor

I grew up in rural Iowa. Our family of twelve had a large vegetable garden tended mostly by my mother. Although it was my father who had grown up on a farm, my mother was a city girl who quickly embraced rural life. She taught her children the love of gardening; how to grow, harvest, and preserve the fruits of labor.

My sisters and I belonged to our local 4-H club where we'd enter our very best green beans, tomatoes, carrots, peas, squash, peppers, onions, and sweet corn as entries to the county fair. Hundreds of blue, red, and occasionally white ribbons adorned our walls. Early on I received the coveted purple ribbon – the championship first place division winner that secured my placement at the Iowa State Fair. Trophies were soon to follow.

As a newlywed, a Minneapolis suburb became home. I worked full time as a registered nurse, took care of the household, and hosted parties. With the help of my husband, I also prepared beautiful raised organic gardens of separate and distinct geometrical shaped designs in our spacious backyard. Soon, three active toddlers were running amongst the designer harvest, snatching snow peas and gobbling strawberries. This was heaven.

Another move to New Hampshire preceded a major, life-altering illness. Who could have predicted that multiple sclerosis would temporarily rob me of sight, hearing and ambulation? As I struggled to raise my children and heal myself, the household became amass with various assistive devices, including crutches, walkers, and wheel chairs. Creativity and my precious gardens seemed to be a part of the past.

As the children grew and left for college, I once again had the yearning to grow my own fresh fruits and vegetables. I had mentioned this to my husband and he offered elaborate designs and planting schemes. But this organic garden had to be mine – from start to finish. It wasn't something I wanted to supervise or observe, but something I could actually get down and dirty with. What was the easiest way to get back to the garden? Keep it simple.

I thought how busy people had patio gardens that didn't even require stepping onto soil. That didn't appeal to me, but the idea of using garden pots or half cedar barrels did. Pots or half barrels fit my height requirement from the wheelchair. I could purchase, haul, and plant them myself. And they were affordable. So I picked the best spot in our yard, eyeballed it for space and sun exposure. Then I picked out the easiest and most satisfying fruits and vegetables to grow in our area. Soon I was off to the market.

My Simple Garden:
4 cedar half barrels
4 bags of 4 cubic feet Miracle-Gro soil
2 tomato wire cone cages
2 dragon fly ornaments
1 slender wooden trellis

Hand tools: fork, shovel, and scissors

Miscellaneous: my old trusty rain stick, kneepad, gloves, and a bug repellant bracelet

With the aid of my scooter, I was able to place the pots with ample space around them to navigate my wheels. Then I clipped the corner from the plastic potting soil bags and carefully poured in the dirt. My trusty rain stick served as a cane to support myself to and from the scooter to fill pots and later to place seeds and set plants. The first year I planted the following:

Barrel # 1: Strawberries; June-bearing in the center, ever-bearing around the circumference; (dragonfly ornament to shoo away critters)

Barrel #2: Tomatoes (within two cones); "Grape" variety and "Early Girl"

Barrel# 3: Trellis placed directly behind the pot; within the soil on the trellis, end was planted with snow peas; front of pot were carrots

Barrel # 4: Half pot was spinach; rest of pot was planted with bush green beans (plus another dragonfly)

Like John Daniel in *The Trail Home*, I meditatively thought… "Drop in the seed and the dirt takes over, the moist warmth, the dark. It's mystery now, out of my hands. But I want to follow. I want to understand what begins to wake the seeds. I want to hear the inaudible moan or hum, that chant of all the lives and parts of lives that dirt composes – I hear it after all, in my mind – that steady call, alive down there, that cannot rise without seeds, that even now enfolds them with its infinitesimal vibration, urging them remember now, remember now, it is time to remember yourself."

As the tomato plants blossomed and then formed green balls, as the snow peas

grew to over six feet tall and green beans bushed out, I began to remember myself again. I thought back to when I was chasing my kids through the geometrically shaped raised gardens. Memories returned of helping my mother pick sweet corn for supper. I reflected on my times in the 4-H. I remembered the perfectly symmetrical unblemished bright red tomato that the judges awarded the coveted purple Iowa State Fair ribbon. And I also remembered that the greatest pleasures are the simplest. Like a garden.

Post-Season Advice from Diana

After enjoying the season's garden, Diana gives this timely advice… "When the fall harvest is complete, gardening tools are cleaned and put away until spring. Now is the time to plan for next year. What worked to improve the garden yield and what didn't work should be evaluated. Don't forget in retrospect, that vegetable that just wasn't worth all the effort. If you have kept a gardening journal along the way, next year's plans are easier to form. A journal makes for good contemplation… and memories of more than just a garden."

About the Author

Diana M. Amadeo generously donated this article for publication in *The Motivator*. She is an accomplished writer, with short stories, features, and articles appearing in more than 400 publications. Her seventh book, *My Sister Amy Is A Premie*, was released September of 2005. Some of her other books include, *A Children's Guide to American Saints* (which came out in October 2005), and *There's A Little Bit Of Me In Jamey* (an overview of lymphocytic leukemia from a child's perspective), published in 1989 and featured on the American Cancer Society's Suggested Reading List. Her novel, *Scarlet Tanager*, a medical mystery, was published in 1995. ◆

Stories to Inspire

The Blessings of Multiple Sclerosis

By Loretta Evans

Eighteen years ago, when I was first diagnosed with MS, I would never have thought there could ever be any good in having a potentially disabling disease. My five children ranged in age from 10 to three. I was feeling overwhelmed by the normal day-to-day tasks that needed to be done.

Looking back, I can see some very positive experiences that our family would never have had without my illness. When my symptoms first appeared, my doctor was looking for things like strokes and brain tumors. I was very much afraid that I would not have long to live. When the MS diagnosis came, I realized that I would probably live a normal life-span, but I wasn't sure how my health might change. Facing those kinds of insecurities made me realize what was really important in my life.

My family was far more important than worldly things like money and possessions. I especially wanted my children to have good memories. On days when I felt good, I didn't spend it cleaning. We would take a simple lunch to the park, or we would go to the library to pick out books to read together. I embroidered pillow cases for each child so that when they were married, they would have something tangible that I had made for them. I knew that memories were far more important than a perfect house.

Because I was unable to do everything I would have liked to do, the children learned to take responsibility early in life. When I was feeling really sick, my husband and my 10-year old cooked supper. My two pre-schoolers learned that they could have fun playing quietly with blocks and puzzles when I needed to rest.

As the children got older, they were able to take on things like mowing the lawn and caring for the vegetable garden. I won't pretend that everything went smoothly and we met every challenge. However, the thing that has impressed me the most has been my children's recognition to take on responsibility, because I couldn't always help.

I have learned to be patient with myself. Before my diagnosis, I felt that I had to be a perfect wife and mother. I believed that I needed to volunteer in the community and play a major role in my church. I have learned to limit my volunteer efforts to those causes I feel strongly about. Maybe I couldn't come into kindergarten once a week as an unpaid aid, but I could certainly make other worthwhile contributions. I could help judge a contest or make a poster. When I taught a Sunday School class in my church, I quickly realized that elaborate visual aids were not necessary. The important thing was the message, and I could still think, read, and talk.

Every time I try to do something, and I find that I just don't have the energy, I still get really frustrated. I am not superwoman. I still pray, "Lord, give me patience, and give it to me right now!" However, I have come to accept my limitations and creatively work within my parameters.

I have the most wonderful husband in the world. His support and care has meant so much to me. He is quick to notice when I start dropping things or when my eyes start to get a glassy look. He lets me rest and takes over whatever needs to be done. I hope that even without MS I would have appreciated what a wonderful man he is, but working through the bad times has really helped us to appreciate the good times.

In the same way that a child who gets overly tired becomes whiny and cranky, I have found that my MS fatigue is often accompanied by depression. On days when I feel ready to burst into tears over every little thing, I realize that the feelings of sadness are only the MS talking. I know that if I can just get enough rest and wait it out, I'll feel better.* By analyzing the things that bother me the most, I am able to zero in on problems that really needed to be solved. When I feel good again, I can then tackle the task, and this improves my outlook.

MS has even given me a new profession. I taught elementary school for six years before my oldest child was born. I had always planned to return to teaching, but I came to realize that I didn't have the energy. I have always loved genealogy and family history. When the children were all in school, I spent long hours learning to put my family information on the computer. I could pace myself, and I never needed to keep going when my energy level was too low. In 1997 I passed the examination to become an Accredited Genealogist. I can now do family history research for other people. It is a perfect profession for me. Most of my business is done by mail or email. I can take on only the amount of work I have energy for. And I love helping other people learn more about their families. If I had been busy teaching school, I would have had very little time for my ancestors.

No one would ever ask for a chronic illness. MS can interfere with so many things that others take for granted. However, I can see that this disease has brought many positive things into my life and that of my family. I have learned to take each day one at a time. A normal day when nothing goes wrong is such a blessing. I would never have known it without MS. ◆

Loretta kindly contributed this inspiring article to MSAA. Many thanks go to Loretta for her generosity.

* The symptoms of depression may not go away on their own. Anyone experiencing depression is advised to consult his or her physician.

Do You Have a Story to Share?

Readers interested in contributing articles for “Stories to Inspire” may send them to **aborkowski@msaa.com** (please include “Stories to Inspire” in subject line), or mail to: Andrea Borkowski, c/o MSAA, 706 Haddonfield Road, Cherry Hill, New Jersey 08002. Please include contact information and permission to print the article, which may be edited for space and content.

Financial Assistance Available for Follow-Up MRIs

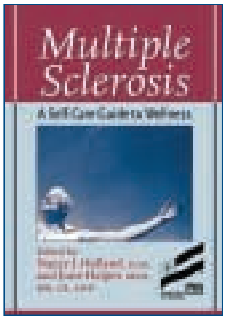
- **A follow-up MRI exam can help you and your neurologist keep pace with the ever-changing course of MS**
- **New information can assist in evaluating disease progression and help find the best treatment options to meet your needs**

The MSAA MRI Institute provides financial assistance in securing MRI scans of the cranium and cervical spine for uninsured, under-insured, or financially challenged MS clients.

To learn more about the MRI Institute, please contact MSAA at (800) 532-7667, ext. 120 or mriinstitute@msaa.com.

The MSAA MRI Institute is supported by a charitable contribution from Serono and Pfizer.

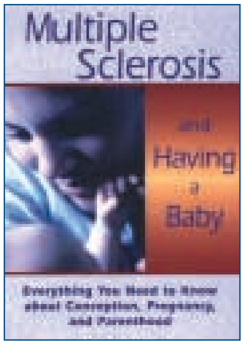
Spread the Word



Multiple Sclerosis: A Self-Care Guide to Wellness (Second Edition)

Edited by Nancy J. Holland
and June Halper
Published by The Paralyzed
Veterans of America and
Demos Medical Publishing, LLC
MSAA Book #264

This is a large, reader-friendly resource covering a full range of topics related to MS, focusing on the needs of those who have had MS for some time. Among others, sections include information on disease and symptom management, health, lifestyle, and community. The aim of this book is to promote maximum independence, wellbeing, and productivity.



Multiple Sclerosis and Having a Baby

Written by Judy Graham
Published by Healing
Arts Press
MSAA Book #73

Author Judy Graham, who has written several other books on MS, addresses the many questions about relationships, health, pregnancy, childbirth, parenthood, and MS. Using the information made available through recent medical research, along with the wisdom of dozens of parents with MS who have successfully raised children, Judy Graham is able to provide factual and helpful answers.

Speedbumps – Flooring It Through Hollywood

Written by Teri Garr,
with Henriette Mantel
Published by Hudson
Street Press
MSAA Book #146

A reviewer of the book notes, “In her laugh-out-loud funny and inspiring autobiography, Teri Garr, one of Hollywood’s best-loved comediennes, muses about movies, men, motherhood, and MS.” Included in this well-written and lively book are several photos of Ms. Garr as she grows up and eventually co-stars with many famous actors in her film and acting career.

MSAA Lending Library

If you would like to borrow any of the books featured in this column or any other book in MSAA’s Lending Library, please send us your name and address. We will send you an application and a list of books for the Lending Library. MSAA and its clients greatly appreciate any donations made to help build the Lending Library. If you would like to donate a book to the Lending Library you need only send it to us at the address below. Please address all correspondence to:

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Attn: Woody Dyer
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Cherry Hill, NJ 08002
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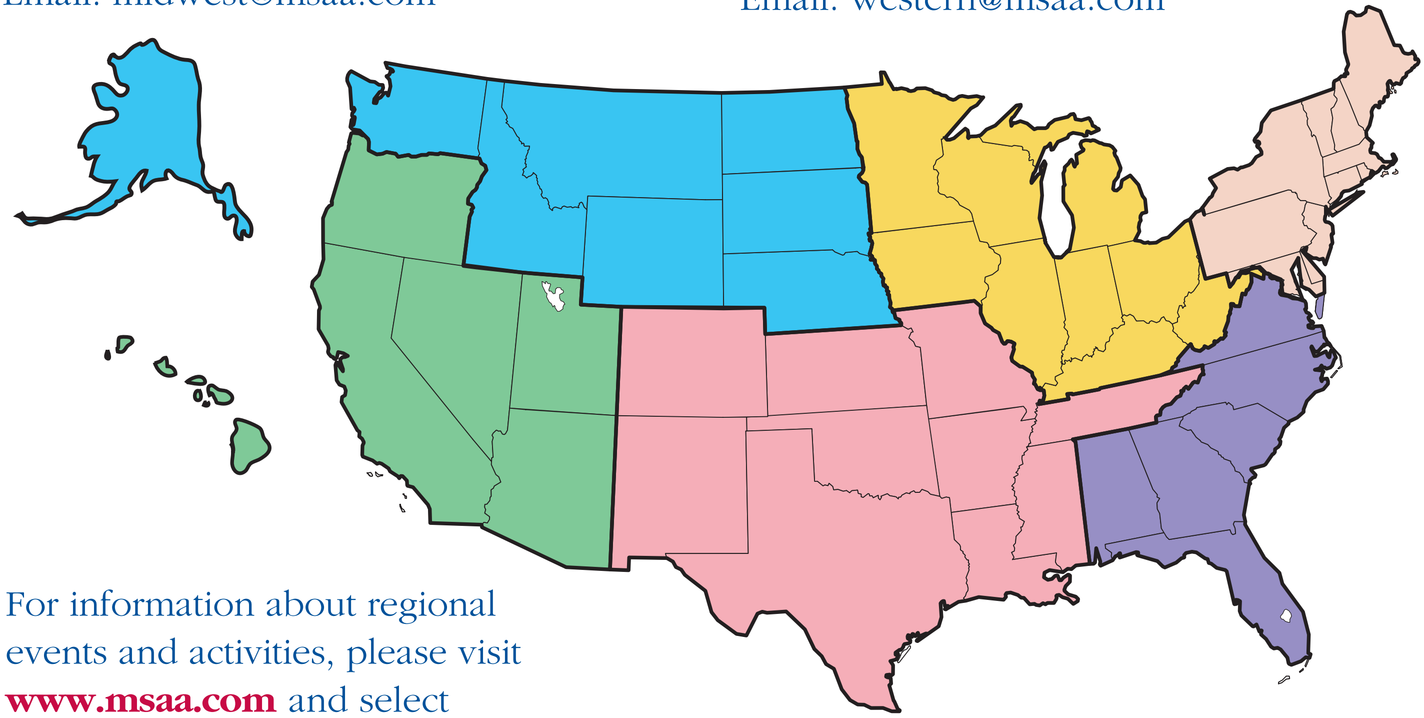

For information about regional events and activities, please visit **www.msaa.com** and select "Calendar of Events & Therapeutic Classes."