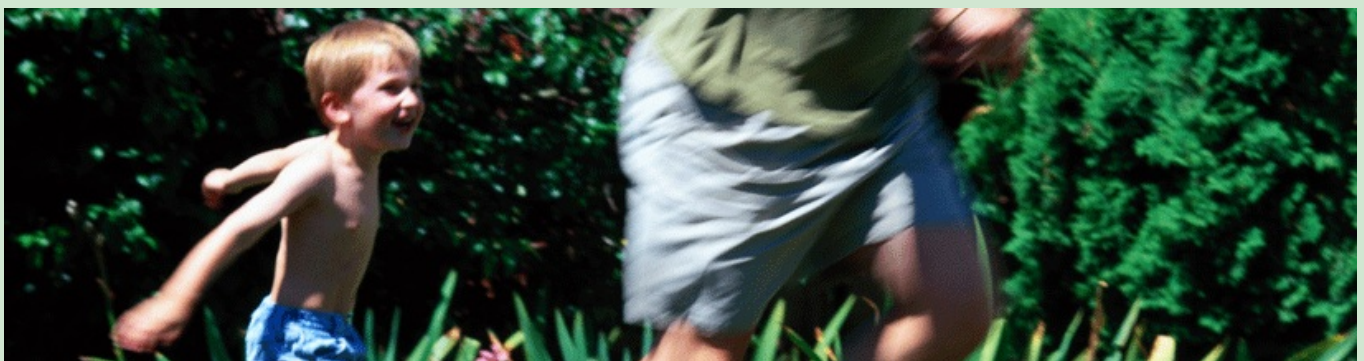




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In Memoriam

Dear Subscriber

Charles Wood



Neuropathy Community Loses Dear Friend and Inspirational Leader

Charles Wood, 78 of Tempe, Arizona passed away on September 1, 2020 at Banner Medical Center in Phoenix. Left to cherish his memory is his wife of 30 years, Barbara Wood. In England, surviving him are his 2 children, his sister, and other extended family members. Charles to those of us that knew him was an inspiration, friend and leader in the neuropathy community. Charles volunteered for the NAF by speaking to countless newly diagnosed Multifocal Motor Neuropathy (MMN) patients, attended numerous NAF events with his amazing wife Barbara, and was a guest columnist for the NAF's "Patient Voice" newsletter. The following was published in a past "Patient Voice" newsletter and is also on the NAF website in our MMN Resource Center. Charles was a true hero and inspiration and will forever be remembered as a kind, generous and caring member of the neuropathy community.

Charles wrote: "The best way to explain the onset of MMN is like someone had flipped a switch and all the electricity containing those very important messages flowing from my brain to the muscles in my arms and legs slowed down; the lights were dimming; the motor was slowly shutting down.

In 2009 at the age of 68, I was still a "regular guy"—working, taking care of my family and home... trying to squeeze in a few moments each day to stay in shape. Little did I know that an insidious neuropathy diagnosis was going to change my life "forever" It all started with a reduction in my grip strength, then in 2010 at the age of 69 I noticed the first two fingers on my right hand beginning to curl under, My family doctor could not give me a diagnosis, so with a referral to a hand specialist and neurologist followed by a series of X-rays, MRI's, EMG's NCV's,



Remember New Year's Eve 2019? As the clock struck midnight and you toasted 2020 you were most likely excited about the year ahead: an overseas vacation, a wedding, a

graduation, a retirement or maybe just a quiet year with family and friends. However, whatever you planned probably has not happened. Instead your 2020 has been consumed with a deadly pandemic, natural disasters, protests, lock-downs, washing and sanitizing your hands and groceries, endless political commercials, and more zoom meetings than ever expected (or wanted). Unfortunately many of us have become immune to bad news and the endless narratives of the pandemic.

The NAF has tried hard to change the narrative for our community by sticking with facts and believing in science. During these challenging times the NAF continues to provide help and hope to patient and their families. As we all work together to change the narrative and to build trust in science we would like to take this moment to be positive and highlight some of our accomplishments. The NAF has accomplished more than we ever imagined possible since our inception. Just a few of our many accomplishments include:

- Provided comprehensive online neuropathy resources that have been viewed by millions from around the world annually which include a bi-monthly "Patient Voice" e-newsletter as well as brochures on various topics like IVIG, Financial Assistance Programs for IVIG and Other Medications, and Complementary and Alternative Medicine Treatments for Peripheral Neuropathy.
- Helped over 1,000 patients with access issues obtaining IVIG and other medications.
- Held twelve "Neuropathy Action Awareness Day" events where thousands have attended in person and thousands more have watched on the NAF website.
- Created a Diabetic Peripheral Neuropathy (DPN), brochure, International Quality of Life (QOL) survey, and public service announcement (PSA) featuring celebrity Jerry Mathers from the classic hit sitcom Leave it to Beaver. The PSA has aired in 39 cities in 23 states.

(nerve conduction velocity tests), followed by an operation where the specialist reported finding a badly bent nerve. He straightened it and recommended electro stimulation therapy (no positive results ensued). Then a visit to yet another "Specialist" who ordered the usual battery of tests including a bone marrow biopsy this time, the prognosis was the same "it's so complicated."

By 2013 (now 72) the symptoms were getting worse, both hands were in fists, my wrists dropped, and my feet were beginning to drop making walking a problem. I could not even sign my name (thank goodness for ATM's) or button a shirt. All my hobbies were now challenges. Then the realization I could not even shave or feed myself. I was referred to another neurologist (my 4th) who, armed with my previous test results spent 90 minutes questioning and examining me before telling me that I may have ALS or some form of peripheral neuropathy.

She referred me to another neurologist whom she considered to be "one of the best in this field". A couple of weeks later I secured an appointment, he examined me and rendered the diagnosis: I had "Multifocal Motor Neuropathy". He informed my wife and me that there was no cure, only a treatment that blocks the symptoms and that I should see significant improvement and eventually only need periodic booster infusions for the rest of my life or until a cure is found. I started my first two-day course of "intravenous immunoglobulin" (IVIG) treatment in January 2014. After some 4 treatments (16 weeks), improvements began to materialize, by August 2014 I was probably back to 80% of my abilities. By November I was at probably 95% and out on the golf course once again. My dosage is now being reduced and I am down to one day every 4 weeks until I reach the level of sustainable health with the minimal amount of treatment.

Right after I was diagnosed. I was having a hard time remembering the long and unusual name of the diagnosis, other than the acronym MMN. What seems so outrageous to me now when I think about this experience is that until my last visit to the neurologist, I was given no written information, no factsheet about neuropathy diseases, and no brochure with the names of resources and support groups ... not even a scrap of paper with the words "Multifocal Motor Neuropathy" scratched across it. The stories I read on the Internet

- Created the first ever MMN brochure and PSA. The PSA has aired in 74 cities in 30 states and has received over 52,000 views on YouTube.
- Featured on ABC, NBC, CNN, IG Living, Neurology Now and many other publications and broadcasts bringing increased awareness to neuropathy.
- Advocated for access to IVIG and other medications via press conferences, legislative hearings, letters of support, coalitions, newsletter articles and traditional and social media.
- Created first ever MMN International Quality of Life (QOL) Survey presented at American Academy of Neurology's 2017 Annual Meeting.
- Multifocal Motor Neuropathy (MMN) campaign that resulted in three patient videos, thousands of new grassroots advocates, and over 1 million ad impressions.

Through our resources and programs, the NAF has become a premiere patient advocacy organization ensuring neuropathy patients obtain the necessary resources to access individualized treatment to improve their quality of life. However, the mission of the NAF can only be sustained through the generosity of people who share our commitment to improve the lives of those living with neuropathy.

The NAF has a strong belief that we will get through these challenging times together and that ultimately science will win.

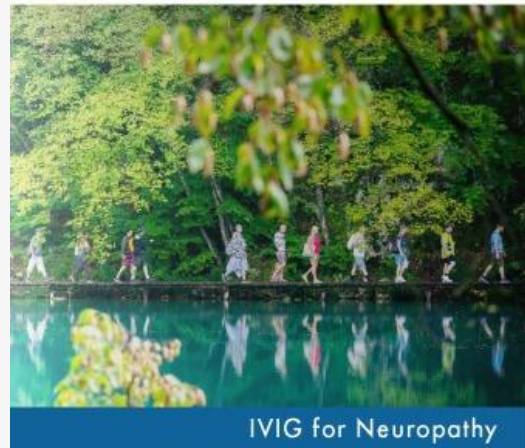
Please partner with us and support the NAF this holiday season by making a tax deductible contribution on-line by [clicking here](#) or go to our website at: http://www.neuropathyaction.org/support_naf/donate.html

Warmest Holiday Wishes,
Dominick V. Spatafora
Founder and President

NAF Creates IVIG Patient Brochure

saturated me with a series of worst-case-scenarios.

My life with neuropathy is more stable and a little easier now. There were setbacks, one of which was finding suitable insurance coverage once my employer provided insurance ceased. We continue to fight, ask questions, seek out answers, and stay strong. I know I have a lot more people to thank, particularly all the plasma donors and people involved in making my IVIG treatments possible and thanks to them in part we now have a fighting chance. Researchers and drug companies continue to work on developing new treatments, “gene therapy” is being investigated as well. Perhaps a cure will be possible soon. The future is full of hope.”



Michelle Greer, RN, IgCN
Jonathan S. Katz, MD

The NAF recently launched a new Intravenous Immunoglobulin (IVIG) patient brochure. Immune globulins are antibodies, a key component of the immune system. IVIG is made from donated human blood plasma. There are many brands manufactured by various companies, and although in general they possess similar attributes, specific manufacturing processes makes each product unique. IVIG treats many different diseases where there is either a deficiency of antibodies or if there is an “autoantibody” where the body starts to attack itself. IVIG is used to treat certain neuropathies that fall into the category of being “autoimmune”. Although there are many types of neuropathy, only a small percentage are the result of an autoimmune condition. Depending on the type, treatment can be short term, long term or for life. IVIG can be a life altering therapy. Most people tolerate the infusions with few side effects, while the physical improvements allow them to live their lives to the fullest.

The NAF would like to thank both Jonathan Katz, MD who is the director of neuromuscular disease program at the Forbes Norris ALS/MDA Center in San Francisco as well as Michelle Greer, RN, IgCN who is senior vice president of sales for Nufactor, a Specialty Infusion Company for their assistance with this brochure. The brochure can be found at:

[http://www.neuropathyaction.org/downloads/IVIG%20for%20Neuropathy-\(Greer-Katz\)NOV-2020.pdf](http://www.neuropathyaction.org/downloads/IVIG%20for%20Neuropathy-(Greer-Katz)NOV-2020.pdf)

Patient Spotlight - Lizz Russell



The NAF is grateful for all the work Lizz Russell has done over the years to bring attention to Guillain Barre Syndrome (GBS).

Lizz has attended numerous NAF events over the years and her passion and desire to help others is contagious! When not helping educate our community on GBS Lizz is a celebrity fashion designer/philanthropist/ and talk show host based in Southern California. She was born and raised in San Diego, CA. Always having a creative spirit and flare for fashion, she began to sew at the age of twelve, and later refined her talents by studying Fashion Design at Mesa College in San Diego.

In the beginning, the journey to become a fashion designer was challenging. There was a lot of preparation, planning and sacrificing in order to move to Long Beach, California with her then 4 year old son at the time. Lizz's sister allowed her to reside with her so she could get her AA degree. Unbeknownst to Lizz, her life was about to change forever at that point. It all started with tingling in her legs and arms, losing weight, and just feeling totally off-balance. Lizz told her sister she felt bad enough to go to the emergency room.

They told her she had a cold and a virus, but Lizz knew it was something else. Unfortunately, she was misdiagnosed several times. It started with temporary paralysis in her face to the extreme weight loss and finally losing the ability to walk and talk....she finally found out months later she had GBS. It's a rare disorder where your immune system attacks the nerves in your body, and there is no cure.

Through strength and support of friends and family, Lizz refused to give up and learned how to walk and talk again. She is role model, liaison and advocate for the San Diego GBS/CIDP Chapter. In addition, to being the chair in the recent – "San Diego's Virtual Walk Benefitting the GBS/CIDP Foundation International".

Lizz Russell is an accomplished award winning author. Her book, "Smiling on the Inside" is an amazing story that is warm, reflective and inspiring to its readers. Lizz Russell shared personal experiences about contracting Guillain Barre Syndrome (GBS). Lizz tells her amazing story in a candid way that resonates in the heart of anyone who has faced sudden illness, affliction or devastating disease. Her second book has been selected to be a part of the Christian Literary Awards in September 2021.

As a philanthropist, she host and created RENEW- where close colleagues and friends donated their professional services to give 25 plus deserving patients beautiful makeovers. Lizz is a firm believer that "every woman should have her own style".

This year, has been challenging but that didn't stop her from starting her own talk show. When you get a chance check out the "Eric and Lizz Show" on YouTube live. This show is highlighting those active professionals out there making a difference and giving back.

Lizz knows this for sure, ***"You don't get what you wish for, and you don't even get what you hope for. You get what you BELIEVE."***

You can follow or contact Lizz at: IG: #lizz_russell_collection - FB:@ lizzrussellcollection - Twitter: @thelrcollection or to learn more about her you can visit www.lizzrussell.com.

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