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NADE

THE ADVOCATE

WINTER ISSUE 2016

A PUBLICATION
OF THE NATIONAL
ASSOCIATION OF
DISABILITY
EXAMINERS

NADE BOARD MEETS IN BALTIMORE FOR MID-YEAR



Photo: Shutterstock

Board members from around the country will meet in Baltimore, MD from February 25 to February 27 for the annual mid-year meeting. They will address issues pertaining to NADE and disability determination. They'll also meet with top SSA officials, including Nancy Berryhill, Deputy Commissioner for Operations; Ann Robert, Associate Commissioner for the Office of Disability Determinations; Gina Clemmons, Associate Commissioner for the Office of Disability Policy and The Honorable Patrick O'Carroll, U.S. Inspector General for SSA.

If you have an issue you'd like NADE to address, either internally or with SSA, please contact your Regional Director as soon as possible!



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A MESSAGE FROM YOUR PRESIDENT



Greetings Colleagues and Friends!

I hope this finds all of you safe and well. The winter certainly has been a historic one for the East Coast. We hope things will get back to normal very soon for those affected. The NADE chapters are very good at seeking out opportunities for service. I have no doubt we will be hearing reports from many chapters who have stepped up to the plate and assisted others during and after the storm.

President Sharon Summers

Since our last issue, the new NADE website (www.nade.org) launched in December. The website has many new features that will be helpful to us as we go about our mission. We are still working out glitches, but this is to be expected. Thank you for your patience as we seek to service all members. Please send a message to your Regional Director if you have problems with any component of the website. We are in the process of scheduling speakers for the NADE MID-YEAR BOARD MEETING February 25-27, 2016. The NADE Board will be meeting with several officials from SSA to engage in discussions on topics of mutual interest. The NADE BOARD will be discussing business issues and developing the TOP TALKING POINTS for the NADE executive leadership to present in Washington, D.C. in March. Please feel free to share any ideas with your Regional Director.

The executive leadership continues to take advantage of Quarterly Conference Calls with Ann Robert, Associate Commissioner for the Office of Disability Determinations (ODD). These calls are essential to keep abreast of ongoing issues and expectations. Likewise, I have kept in touch with Erick Williamson, President of the National Council of Disability Determination Directors (NCDDD) to discuss items of mutual concern and interest.

Our upcoming National Conference in Aurora, Colorado is August 14-17, 2016. Please start planning to send delegates from your chapters. Hopefully, we will have more information soon as to the number of funded delegates your Director can send. If you have never been to a NADE Training Conference, please plan to attend and take advantage of the wealth of educational opportunities, the professional networking, and the friendships that abound. Our training conferences are state of the art. Watch for the Agenda to post to the website in the next few months. Registration will begin sometime in March. Your Regional Director will keep you updated.

Finally, I will leave you with this thought, "The future never just happened. It was created." –Will and Ariel Durant. NADE's future depends on your creativity.

NADE LETTER TO NANCY BERRYHILL



February 1, 2016

Ms. Nancy Berryhill
Deputy Commissioner of Operations
Social Security Administration
6401 Security Blvd.
Baltimore, MD 21235

Dear Ms. Berryhill:

On behalf of the National Association of Disability Examiners (NADE), we congratulate you on receiving the Presidential Rank Award. This award demonstrates the dedication and service you have given to the public and it is well deserved.

NADE always appreciates your willingness to share your message with us whenever there is opportunity. The information keeps us informed and prepared. Our members always look forward to your presentations. We look forward to meeting with you again soon.

Our very best wishes to you as you continue to develop ideas and processes that positively impact the service level of Social Security Operations. The public is better served because of your dedication.

Sincerely,
Sharon Summers
NADE President

PUTTING A FACE TO A CLAIM: MY SISTER

By Korin Gary

My sister Alison played the upright bass in elementary school. She loved it. By middle school, she played both upright and electric bass. I'd moved away to college by then, but I admired her hutzpah. Not every little girl can jam on the bass.

Then I heard she'd developed a problem in her wrist, a problem that would not go away, despite any treatment she tried. She had to give up the bass, to her great disappointment. Over the next couple of years, she experienced more pains and frequent injuries. She visited doctors who said, "You couldn't have injured yourself badly by doing that. I don't know why you're still hurting." Since the family trusted these providers, we speculated that Alison had a low threshold for pain, or maybe her emotional pain manifested as physical pain. She was a teenager at the time, after all.



My sister and me hamming it up, around 1993

Alison graduated and went to college out of state. Her problems with pain continued, and became so commonplace that both she and we just came to accept them as part of her life. Finally, though, during one of many physical therapy appointments in 2007, her physical therapist noticed Alison's joints were hypermobile. Alison was 23 at the time. "Oh," I thought. "Finally, we know what the problem is! Now someone will be able to fix it." But, no. The common recommendations for hypermobile joints include elevating, icing, and heating the joints. Soon, Alison was employing these measures on a regular, then constant basis.

In 2011, she fully dislocated her shoulder in her sleep. She couldn't keep her shoulder in place after that. She learned to reset it herself and move on, but muscle spasms and pain wracked her body. She began to experience blood pressure and pulse irregularities, digestion problems, and temperature dysregulation. Doctors were baffled, and referred her to specialists, including a cardiologist who diagnosed her with dysautonomia. In 2012, an orthopedist told her she wasn't a candidate for surgery because she had Ehlers-Danlos Syndrome (EDS). This was the first Alison had heard of EDS, now about 15 years after her first symptoms emerged. Her primary care physician subsequently ruled it out, though, because he said it was too rare a condition for her to have. She asked for a referral to a rheumatologist, but her doctor refused.

During yet another physical therapy session, her collarbone popped out at the sternum and several ribs shifted grotesquely.

(continued, page 4)

PUTTING A FACE TO A CLAIM (cont.)

"I returned to my doctor," she writes. "He looked aghast as I lifted my shirt to expose my red, bruised and lumpy ribcage. He poked at my ribs and I socked him in the mouth out of reflex. I apologized profusely and he promptly referred me to a rheumatologist." That rheumatologist diagnosed her with Benign Joint Hypermobility Syndrome and a bad case of chostochondritis.

But, she had symptoms that couldn't be explained by either condition. She vomited several times per week without warning or provocation. She was clumsy, and physical therapists noted terrible proprioception. And, her symptoms appeared to be accelerating quickly. Her quality of life deteriorated fast. At every step of the way, providers refused to believe her, and labeled her a hypochondriac and a drug-seeker. Alison felt discouraged, frustrated and misunderstood.

Despite it all, she graduated from law school and passed the California Bar Exam. She took a job in a prestigious Washington, D.C. law firm. There, she found an international expert in EDS, and she finally got her diagnosis: EDS III.

She writes, "EDS is a family of genetic connective tissue disorders. There are at least seven types with severity ranging from so mild it will never be diagnosed, to total disability or death. Hypermobility Type III is the most common type. I have a moderately severe case.

"My time in DC was rough. Between September, 2012 and April, 2013 I suffered several full and partial dislocations of new joints: my wrist, my finger, my elbow. They happened so often that I stopped seeking medical attention for them. I dislocated my patella while waiting for the metro in April 2013. Later that week, I dislocated my tibia at the knee and ankle by moving it with my own hands!

"A few months later, in October, I woke up with the worst stiff neck of my life. The pain subsided over the next few weeks, but neurological problems emerged and then intensified. By December 2013, I had severe memory and judgment impairment. I could not balance and had no reaction to pinprick tests. I had no gag reflex and constant nausea; I had trouble with word finding, and was extremely drowsy. A neurosurgeon specializing in EDS patients diagnosed me with craniocervical instability and Cervicomedullary Syndrome in February, 2014. This is a very rare condition. My skull slides forward on my neck and impinges my brain stem. I had a C1-C2 fusion and other partial measures in October 2014. The surgeon instructed me never to look down because my skull will pinch my brain stem and cause many of my symptoms to return."

At 29 years old, Alison lost her job at the law firm, and her ability to work in any job. Her neurological symptoms improved slowly, but her constant pain continues. She has very little energy, and must budget it carefully every day. She can't drive.

She is currently halfway through her two-year recovery period from her surgery, but she'll need to wear a cervical collar part-time for the rest of her life and may eventually need more surgery to further correct the Cervicomedul-lary Syndrome.

(continued, page 5)

PUTTING A FACE TO A CLAIM (cont.)

My whole family mourned my little sister's disability. In my life, I flew pretty close to the ground: a safe school, a safe career, etc. But, Alison soared high. She set bold, ambitious goals for herself and achieved every one. She earned admittance to one of the best colleges in the country, studied abroad, and landed a position in a prestigious law firm in the nation's capital. I cheered for her every step of the way. When she lost it all, I cried. She's very brave, and keeps a positive attitude most of the time, but she suffers more than anyone should, and sometimes the seeming unfairness of it all makes me angry and sad.

The prevalence of EDS was estimated at 1:20,000 in 2001, but the incidence appears to be on the rise, now estimated at 1:10,000 (G. Defendi, MD), due to the genetic component of the disease, or better identification, or both. Statistically, the odds of one of these cases crossing your desk improve every year.

Alison meets listing 14.06, "Undifferentiated and Mixed Connective Tissue Disease" under Immune System Disorders. Please see Dr. J. S. Pritchard's companion piece to this article about the listing, on page 7.



Alison and her husband, today

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MIXED CONNECTIVE TISSUE DISEASE: UNRAVELING THE MYSTERY

BY Dr. J. Scott Pritchard, NADE Medical Consultant

Undifferentiated Connective Tissue Disease (UCTD) is an autoimmune disorder. A heightened immune response damages connective tissues that support the skin, eyes, major organs and cartilage.

UCTD is a syndrome in which there are not enough features of a <u>specific</u> autoimmune disease (rheumatoid arthritis, for example) to be clinically classified. Symptoms, diagnostics and clinical findings are thus "undifferentiated." Studies estimate that 25% of all patients seen by rheumatologists have UCTD. The majority of individuals with this complex do not develop a <u>specific</u> connective tissue disease.

Photo: Shutterstock

In overlap syndromes such as Mixed Connective Tissue Disease (MCTD), there are typically specific features of at least three separate disease entities: rheumatoid arthritis, myositis and scleroderma, for example.

Symptoms include arthralgias, arthritis, rashes, photosensitivity, alopecia, Raynaud's phenomenon, ulcers of the mouth, dryness of the mouth/eyes, low-grade fever and photosensitivity.

Diagnosis of UCTD/MCTD is elusive. An individual's symptoms are often linked to other disease processes. In the absence of a unifying diagnosis, providers often consider psychogenic etiologies like somatoform disorder, anxiety or substance addiction.

Signs and symptoms suggestive of UCTD that do not meet the criteria for any other connective tissue disease must have been present for at least three years in order for a provider to consider UCTD/MCTD as a diagnosis. The presence of a +ANA must be present on two separate occasions. This too, often results in delayed diagnosis.

The diagnosis is ultimately one of exclusion. The often vague and overlapping symptoms are confounding to the individual and difficult to unravel for the treating source.

If you have a claimant with these very vague symptoms, a long history of consistent complaints and a + ANA, consider listing 14.06 A or B. You may be able to meet or equal this listing for the claimant.

FRAUDBUSTERS: OREGON

The Salem CDI unit investigated a 41-year-old man who applied for Title II and Title XVI disability benefits alleging chronic pain due to severe back issues and cracked pelvis. He reported that he couldn't lift his legs to put his pants on, and needed assistance from his wife for to dress and bathe. He could only cook by rolling around in a chair. He stated that his home was falling apart

due to his inability to make repairs.

Investigators observed the claimant driving and walking along a city street with a normal gait. During their 34-minute interview, claimant stood the entire time, and at one point bent at the waist to retrieve something from the pavement. He stated that he'd worked in masonry for 10 years and had recently begun buying and fixing up rental properties. The claimant said he and his wife, a Supplemental Security Income recipient, manage 32 separate properties and own several



Photo: Shutterstock

of them. The claimant described personally doing the remodeling which included replacing the flooring, sheetrock, masonry work, painting and other work. The claimant displayed pride in discussing his current business situation and said it had become a full time job.

Oregon DDS denied the man's application for disability benefits. This case has been referred for possible Civil Monetary Penalties.

FRAUDBUSTERS: SOUTH CAROLINA

The Columbia CDI unit investigated a 59-year-old woman who applied for Title II and Title XVI benefits for vision problems and mental issues. South Carolina DDS referred the case when the examiner suspected the claimant was malingering based on her reported activities. The woman claimed she was unable to complete basic daily activities and complex tasks due to her conditions.

CDI investigators discovered from the woman's Facebook page that she offered voice and piano lessons for \$75 per hour. During a ruse interview, the woman admitted that she currently had seven students and performed piano concerts at local nursing homes. She added that she drove to five of her students' homes to provide lessons for an extra \$25 per hour. Investigators located witnesses at a nearby nursing home who confirmed that the woman routinely drove to the facility to perform concerts where she sang and played piano.



SC DDS denied the woman's application for disability benefits.

FRAUDBUSTERS: ARIZONA

The Phoenix CDI unit investigated a 54-year-old man who was currently receiving Title II disability benefits for statutory blindness. During the course of his Continuing Disability Review, the CDI unit received an anonymous tip that the man was working and playing in a competitive tennis league.



CDI conducted an investigation of his DMV records and found that he owned a car, and had answered, "No," to the question on his driver's license application asking whether he had a visual impairment that would affect his ability to drive.

CDI also established surveillance at a tennis match where the man was competing. He appeared to be a strong tennis player as he rarely missed the ball and made successful serves. He did not appear to struggle with any visual impairments and wore no glasses or visual aids.

SSA ceased the man's disability payments due to medical improvement. The Office of Counsel to the Inspector General subsequently accepted this case for civil monetary penalties.

NADE MEMBERSHIP: STRENGTH IN NUMBERS

By Melissa Williamson, Membership Director

"Alone, we can do so little; together, we can do so much." - Hellen Keller

NADE embodies this quote from Ms. Keller. Alone, each of us has a single voice. Together, we are many voices helping SSA shape the future of disability determination. When NADE speaks, SSA listens.

Your NADE membership provides you with many opportunities to become more educated about the disability program. We offer training conferences that focus on medical, vocational and policy issues. These conferences also give members the opportunity to hear SSA officials speak and ask them questions regarding upcoming SSA changes.

NADE also provides leadership opportunities. At the local, regional and national levels, NADE encourages everyone to be active and take leadership roles. Committee chairs, board members, etc., are always needed. Join a committee today, and work toward our common goals!

I encourage each chapter to set a goal to increase your membership by adding at least 5 new members. Educate the non-members in your DDS about NADE. Encourage them to go to the new NADE website so they can see first-hand all that NADE has to offer. Show potential members *The Advocate*, especially the recent Conference edition.

Chapter Presidents, please remember that you can request a Membership Grant to assist you in your recruiting efforts. This is available year-'round; each chapter is eligible for one grant per year. To request the grant, please email Melissa.Williamson@ssa.gov or NADE.Membership@gmail.com with a description of your recruitment plans or activities.

Let's all work together to grow NADE's membership numbers this year!



DAVE SMELSER: A MAN OF MANY HATS

BY DONNA HILTON

As a retiree, I can attest that it is easier to look back and remember the people who have made significant contributions than to recall where you laid your keys this morning. One person who has been invaluable to our organization is Dave Smelser. Dave became a NADE member shortly after he joined the Missouri DDS. His name may not be familiar to many members because he worked largely behind the scenes, but he worked for NADE as the publisher of *The Advocate*, our membership contractor, and our webmaster for over 20 years.

It all began back in 1992 when the Publications Director stepped down and NADE started looking for another member to step up and assume those responsibilities. At the time, Sheila Wrinkle and I were working on building our Missouri chapter membership. Sheila called me to say she had heard the Publications position was open and suggested that Dave might be a good fit for the job. I visited Dave and explained what was involved and asked if he was interested. He was interested in the mechanics of the job but didn't think he was the right person to attend board meetings and give reports in front of conferences. Instead, he turned the tables on me and suggested that if I sought the board position, he would work with me behind the scenes.

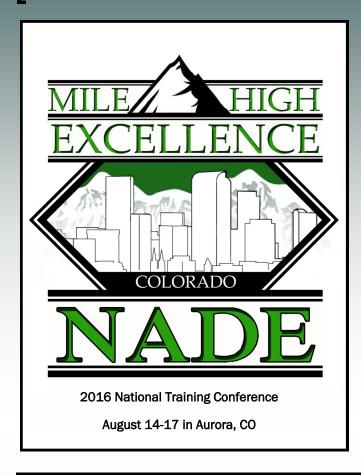


Photo: Shutterstock

We immediately decided the old publishing method of typing, cutting and pasting layouts was too time consuming for our schedules, so Dave moved us into the computer age. He secured the PageMaker program, which was very technical, but in a few months he became comfortable with it. He had always been a hobby photographer, but his work with *The Advocate* spurred him to turn his hobby into a professional occupation. A new innovation, the digital camera, arrived and made significant changes to the publishing process. As his digital skills grew, Dave improved the quality of photos for *The* Advocate, and it moved from a newsletter to a truly professional journal.

A few years later, the NADE Board announced it was taking bids for the position of membership contractor, a job that required oversight of the membership dues, keeping the database up to date and providing monthly reports to the Board and the NADE chapters. Dave was awarded the bid and has kept the membership rolls since then. As NADE desired further expansion into the electronic age, Dave provided the building blocks. He became the designer and later the webmaster for the NADE website. Professional training was time-consuming and web creation expensive for the new Internet world, but Dave worked to provide NADE with a quality product at a reasonable price that our organization could afford.

Each of the hats Dave has worn over the years in working for NADE has required a great deal of on-the-job training, and each year he rose to not only meet, but exceed the demands of each new challenge. He continually looked for ways to improve our image and get our message delivered with a cost-effective process. Our organization owes Dave a great debt of appreciation for his service and commitment to promoting the National Association of Disability Examiners. We wish Dave well as he moves on to new projects and challenges!



PLANNED EXCURSIONS

Sunday: Tour of historic Boulder

Monday: Dinner at Central City Casino

Tuesday: Dinner at a local restaurant



HOTEL: RADISSON HOTEL, DENVER SE

WEBSITE: cadeonline.net

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Chapter News From Around the Nation

TENNESEE CHAPTER HELPS SOUTH CAROLINA CLAIMS EXAMINER by Jessica Marshall, TADE president

Each year, as the weather begins to get cooler, TADE hosts a chili cookoff. This year, TADE members decided that the proceeds from the cook off should be donated to SCADE to aid an examiner whose home was severely affected by the flooding there.

TADE encouraged TN DDS employees to enter their homemade chili for the cook off. We had a total of 8 entries, and enlisted 3 judges. Winners received a 1st, 2nd or 3rd place ribbon and a gift certificate.



Photo: Shutterstock

The day of the cook off was a perfect day for a warm bowl of chili, and we had an excellent turnout! TADE raised a little over \$200.00 and sent it to the president of SCADE, Dr. Rebecca Merriweather. She emailed us just before the holiday vacation to say that the money had reached our intended recipient. We were so glad to know that we helped a fellow member in need, just before Christmas.

COLORADO CHAPTER ADOPTS FAMILY OF FIVE by Ruann Parker, CADE past president



For the last several years, CADE has supported the Salvation Army's "Adopt a Family" program. This year CADE "adopted" a family of 5 from the local community. CADE donated \$250 to purchase the items on the family's wish list. Then we collected cash, gift cards and other gift items from the staff. The total estimated value of the gifts was \$1350, which included \$385 in gift cards.

CADE also promotes the "Toys for Tots" campaign through the US Marine Corps. We collect toys and gift items from the staff each year. This year we donated 53 fabulous toys to the program. It is heart-warming to see the gifts and donations made to both organizations.

Chapter News From Around the Nation

LANSING CHAPTER GIVES TO WOMEN By Sonya Sanford-Quinney, LMADE president



In December, the Lansing sub-chapter of MADE collected gifts for the Above the Water House, a transitional home for women recovering from drug and alcohol addiction.

Grateful owners of Above the Water House (left) pose with Sonya Sanford-Quinney (right)

FAIRFAX CHAPTER DONATES COATS AND OTHER SUPPLIES by Vida Cyrus, VADE member

In November, the Fairfax sub-chapter of VADE collected coats, hats, scarves and gloves for The Lamb Center, an organization that serves homeless people. We've made two trips to drop off donations so far, with a third planned!



OrADE GIVES TO KIDS by Korin Gary, OrADE president



In December, OrADE worked with the U.S. Marine Corps to collect and donate new toys for kids of all ages. We tried to pay special attention to teens and tweens, since they are sometimes forgotten during toy drives. All told, we collected two extra-large boxes of toys and \$271.41 in cash donations.

Opportunities Abound in Oregon!

Oregon DDS will soon recruit experienced Examiners, Medical Consultants and a Systems Manager.

Join our innovative, successful and results-oriented staff in Salem, Oregon's capital city. Oregon offers many cultural and outdoor activities. The beautiful Oregon Coast, the Cascade Mountains, and metro Portland are each just an hour away!



Examiner Salaries: \$3,339 - \$5,355/mo

Medical Consultant: \$7,127 - \$10,462/mo

System Manager: \$5,894 - \$8,687/mo

... plus generous benefits!

Find applications for Examiners, Medical Consultants and a System Manager at: http://www.oregonjobs.org.

For more information on Examiner positions, please refer to the recruitment at: https://www.governmentjobs.com/careers/oregon/jobs/1316993/disability-analyst-2-disability-analyst-1-underfill-option. You can also contact Jay Minten at 503-986-4803 or jay.minten@ssa.gov before the close date: 01/12/2016. We plan to hire additional examiners later this year also.

For more information on Medical and Psychological Consultant positions, please refer to the recruitments at https://www.governmentjobs.com/careers/oregon/jobs/1316149/medical-consultant-medical-consultant or https://www.governmentjobs.com/careers/oregon/jobs/1316706/medical-consultant-psychological-consultant. You can also contact Heather Emberson at 503-986-4941 or heather.emberson@ssa.gov before the close date: 01/19/2016.

For more information on the System Manager position, please contact Mary Gabriel at 503-986-4809, <u>mary.gabriel@ssa.gov</u> or Ken Forbes at 503-986-4877, <u>ken.forbes@ssa.gov</u>. Tentative start date: June 1, 2016.

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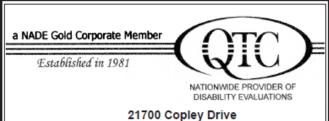
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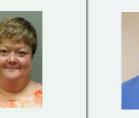
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Strategic Plan

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