

Helen

The Journal of Human Exceptionality

ISSUE NO. 6
NOVEMBER 2022

Sleep Series
The
FIRESTORM
of
Rare Epilepsy

ON THE
Nobility
of Incontinence

plus
Building a Village
OF Support

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Susannah Rosen. Photo by Luke Rosen



Helen

The Journal of Human Exceptionality

Helen: The Journal of Human Exceptionality is where people with disabilities, families, clinicians, and caregivers intersect for inclusive health.

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Collaborative Organization Mission Statements

Helen: The Journal of Exceptionality is proud to be endorsed by the nation's leading organizations that advocate for people with Intellectual and Developmental Disabilities (IDD).



The AADMD is resolved:

To assist in reforming the current system of healthcare so that no person with IDD is left without access to quality health services.

To prepare clinicians to face the unique challenges in caring for people with IDD.

To provide curriculum to newly established IDD training programs in professional schools across the nation.

To increase the body and quality of patient-centered research regarding those with IDD and to involve parents and caregivers in this process.

To create a forum in which healthcare professionals, families and caregivers may exchange experiences and ideas with regard to caring for patients with IDD.

To disseminate specialized information to families in language that is easy to understand.

To establish alliances between visionary advocacy and healthcare organizations for the primary purpose of achieving better healthcare.



It is the purpose of the American Academy of Developmental Dentistry (AADD) to establish postdoctoral curriculum standards for training dental clinicians in the care of patients with IDD, to establish clinical and didactic training materials and programs to promulgate these standards, and through its certifying entity – the American Board of Developmental Dentistry – to grant board-certification to those dentists who have successfully completed these training programs.



The American Academy of Developmental Medicine (AADM) is a medical society dedicated to addressing the complex medical needs of individuals with intellectual and developmental disabilities across the lifespan. It incorporates clinician training and awareness, teaching, advocacy, research, board certification, health equity, interdisciplinary collaboration, inclusive care delivery models and shared decision making.



AAHD is dedicated to ensuring health equity for children and adults with disabilities through policy, research, education and dissemination at the federal, state and community level. AAHD strives to advance health promotion and wellness initiatives for people with disabilities. AAHD's goal are to reduce health disparities between people with disabilities and the general population, and to support full community inclusion and accessibility.



On the Nobility of Incontinence

When I was growing up, guys' names had a certain ring to them. "Duke" still conjures up someone you want behind you in a schoolyard brawl, while "Spike" makes a decent back-up if Duke wimps out. You'd likely agree that "Rock" would be the one to call if you had to get your bike back from the kid who stole it; the delinquent thief's name would probably be something like "Biff" or "Mack."

You definitely wouldn't feel confident with a "Stanley," "Bernie" or "Alfred" backing you up if you had to walk through a schoolyard claimed by a gang of guys wearing black leather jackets, boasting their membership in the "Eastside Cut Throats" social club. Yeah, guys' names have a ring about them. But sometimes, names don't pan out. Sometimes, when you're looking for constructive help, it doesn't come from the place you'd expect. "Alfred" is certainly not a power name like Duke, Spike or Rock.

Yet, a guy named Alfred became synonymous with power. He, in fact, unleashed such power that the world had never known. In 1867, Alfred, a Swiss chemist, figured out that when nitroglycerin was mixed with an

absorbent, inert substance, it became stable and safer to handle. Realizing he was onto something marketable, he considered naming the powerful substance "Nobel's Safety Powder." Instead, he came up with "dynamite," referring to the Greek word for power. And power was indeed what he amassed—power and fortune.

Thirty years later, Alfred Nobel signed his last will and testament, giving a large share of his fortune to fund a series of prizes bearing his name, stating:

"The whole of my remaining realizable estate shall be dealt with in the following way; the capital shall be invested...the interest on which shall be annually distributed in the form of prizes to those who, during the preceding year, shall have conferred *the greatest benefit on mankind*... one part to the person who shall have made the most important discovery within the domain of *physiology or medicine*."

Thus, the Nobel Prize in Medicine was first conferred in 1901. There is no doubt that this prize has served as a testimony to the greatest medical advances and researchers the world has seen. All game changes, without doubt: Koch's (1905) identification of the tubercle bacillus and related work

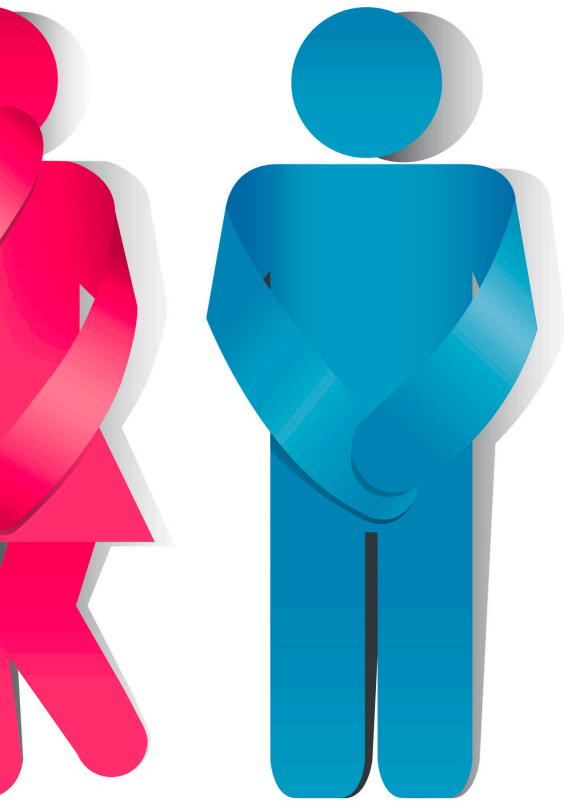
on tuberculosis; Landsteiner (1930) on blood groups, and blood typing; Fleming, Chain, and Florey (1945) for penicillin; Crick, Watson, and Wilkins (1962) on the discovery of DNA; Banting and Macleod (1923) for the discovery of insulin; Murray and Thomas (1990) on organ and cell transplantation. It may be that anyone reading this has benefited, directly or indirectly, from the work related to one of the 113 Nobel Prizes awarded in medicine.

While the Nobel Prize in Medicine is certainly significant, why are we referring to it in *HELEN: The Journal of Human Exceptionality*, a publication dedicated to a better understanding of the disability community—and in an article about incontinence? Answer: to make an important point. Help doesn't always come from the place you'd expect. A careful survey of the prizes reveals that not a single one has been given for any significant work in the treatment of incontinence.

While each of us hopes a cure is still on some researcher's bucket list, to date, there has not been any Prize-worthy game-changing work on this condition. If we were to look to the big names right now—the Dukes, the Rocks, the Macks, and the Nobels—we'd find little concrete help.

But just suppose that there was a great advance. It's not so far-fetched.





The consequence of incontinence extends far beyond embarrassment. Around 13 million people in the U.S. have been diagnosed with incontinence, according to the Agency for Healthcare Research and Quality. While older age increases the risk of this condition, there is a wide range of factors that can cause this problem in younger persons. People with disabilities often experience incontinence as a co-occurring condition. It provides a major obstacle for full participation, inclusion and engagement for people in the disability community.

Recently, Richard Craver, writing in the *Winston-Salem Journal*, reported that researchers at The Institute of Regenerative Medicine, Wake Forest University, produced the first functional anal sphincter in a laboratory setting. When we're talking about a sphincter, we need to recognize we are at its mercy. Current treatments available for restoring damaged sphincters all have high complication rates and limited success. These sub-optimal

treatments have included skeletal muscle grafts, injectable silicone material, or implantation for mechanical devices. No candidates here for a trip to Stockholm and a share of a \$1.5 million Nobel Prize.

But now, according to Professor Khalil Bitar, one of the lead researchers involved in the work mentioned above, "In essence, we have built a replacement sphincter that we hope can one day benefit human patients. This is the first bioengineered sphincter made with both muscle and nerve cells, making it pre-wired for placement in the body."

If, in fact, a workable and sustainable bioengineered replacement sphincter could be perfected, how would it stack up for a Nobel Prize? It is hard to tell. Would it become a named advancement? Would capturing the Nobel Prize for this achievement make a difference in people's lives?

The fact is that we're not where we'd like to be with the science. We're not sure how soon we're going to get there. So, in the meantime, this article, which originally appeared in the book *Managing Life with Incontinence* (The Simon Foundation for Continence) engages the reader in the reality, the mythology and the experience of living, fearing, cursing, adjusting to, and accepting the intrusion of a defiant sphincter and the prospect of adapting successfully to the "new new" that it imposes.

Incontinence and its impact are fairly complex, and I like simple. As a medical student, "simple" was my ticket to appreciating the synergy of the body's complex systems. When we

hit Chapter 26 of Guyton's physiology text (imagine no mention of "elimination" until chapter 26), I was confronted with some heavy-duty illustrations and intense physiological principles, I needed "simple." I quickly realized that in the physiology of elimination, the sphincter was the key. It was the body's equivalent to the ice hockey team's all-important goalie, with the puck representing both urine and feces. Take your eye off the puck and you're incontinent.

The "simple" (but eloquent) explanation for the role that the sphincter plays came to me by way of an unforgettable British physiology professor who stated:

"They say man has succeeded where the animal fails because of the clever use of his hands, yet when compared to the hands, the sphincter ani (anal sphincter) is far superior. If you place

into your cupped hands a mixture of fluid solid, and gas and then through an opening at the bottom, you try to let only the gas escape, you will fail. But the anal sphincter can

“Incontinence provides a major obstacle for full participation, inclusion and engagement for people in the disability community.”

do it. The sphincter can apparently differentiate between solid, liquid and gas. It apparently can tell whether its owner is alone or with someone, whether standing or sitting down, whether its owner has his pants on or off. No other muscle of the body is such a protector of the dignity of man, yet so ready to come to his relief."

As quoted from Dr. Walter C. Bornemeier, protector of the dignity of man for sure, the anal sphincter, and its urinary counterpart, also have the capacity to decimate and forever change the landscape. Too bad that

adverse impact hasn't gotten more attention.

To answer the question as to whether a bio-engineered sphincter could walk away (maybe that's asking too much of any sphincter, natural or engineered) with the Nobel Prize, we have to look at popular culture and incontinence.

Incontinence remains one of the last stigmatized targets of a dysfunctional body system. To be realistic, the working, functioning sphincter doesn't really have an identity." We don't characterize it, we see it neither as an unsung hero, nor a team player. It simply exists without any persona. Perhaps its invisibility is a testimony to the hundreds of millions of lives in which it quietly goes about its business of "protecting the dignity of man." None of us sing praises to a hearty sphincter. If anything, we praise our own self-control (so little do we know about what is happening behind the scenes) in making it to the restroom in the nick of time. Muscles, hearts, erectile dysfunction, healthy lungs all get good face time. But in our culture, the sphincter has no advance men, no PR department, and no creative department ready to pitch an unforgettable tag line, no one to give it a pop personality.

But let forget its ninja skills and it becomes not only apparent, but the center of attention. An impaired sphincter can reconfigure lives that were doing just fine before it abandoned its sentry post. It can redefine lives. Lives that never gave the darn "thing" (one does not want to personify a traitor) a thought, now must plan, scheme, schedule, prepare, anticipate, and compensate in ways that would impress Harry Potter.

In spite of the above, the unfortunate truth is that an announcement that a synthetic replaceable sphincter has been perfected would not raise an eyebrow at the Nobel Prize Nominating Committee. The simple fact is that in a world awash in information, there is no awareness, no notoriety, no celebrity spokesperson, no highly visible

centers of excellence, and no visibility for the impaired sphincter and its outcomes, incontinence. Worse still, it's that there is no mandated curriculum in medical schools, never a question on board exams for doctors, no challenges to the interns on ward rounds, and very few support groups. So, this article (and the aforementioned book), and the information that it both invites and provides, is an attempt to fill the gap and hasten the change.

The book *Managing Life with Incontinence* will help individuals with incontinence, their families, significant others, health care providers, policy makers, and perhaps songwriters, playwrights, and poets navigate the reconfigured lives that are possible for all of us.

As for my hope for the Nobel Prize Nominating Committee to one day recognize and celebrate either a cure or successful treatment for incontinence, I would like to refer back to the prize medal itself and its irony. The medal of the Nobel Assembly at the Karolinska Institute depicts the Genius of Medicine holding an open book in her lap, collecting the water pouring out from a rock in order to quench the thirst of a sick girl at her side. If the image of water pouring onto a girl's lap is not reflective of incontinence, I don't know what is. Maybe that's what we needed all along to spur the science in this area, for the Nobel Committee to read its own subliminal message, that cures must be found for incontinence.

Finally, in support of my argument for full Nobel recognition at the time a cure is announced, I present the inscription on the Nobel Prize medal, "*Inventas vitam juvat excoluisse per artes.*" Loosely translated, "And they who bettered life on earth by their newly found mastery." A fitting inscription for the person or persons who provide the definitive treatment for incontinence. Until then, it is the hope that this article and future pieces on continence will inspire robust research.

Why Helen



*Alone we can do so little;
together we can do so much.*

- Helen Keller

HELEN: The Journal of Human Exceptionality pays tribute to Helen Keller. Ms. Keller is perhaps the most iconic disability rights advocate and an example of how an individual with complex disabilities found and used her stamina, perseverance, resilience and determination to accomplish great things.

Helen personifies the spirit, mission and vision of *The Journal of Human Exceptionality*. Her remarkable life is a reflection of her determination; she inspired us with her words, "What I'm looking for is not out there, it is in me."

"Nothing is written."

This quote from T.E. Lawrence implies that nothing is inevitable, life consists of choices, and how the individual can make an impact on his/her destiny. The disability community continues to reinforce and remind me of this; hence the name for my monthly musings.

- Dr. Rick Rader

(From the Preface, On the Nobility of Incontinence, Rick Rader, MD, Managing Life with Incontinence, The Simon Foundation for Continence, Copyright, 2012; Dr. Rader is a member of the Board of the Simon Foundation).

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Administration for Community Living

*Advancing independence, integration,
and inclusion throughout life*

ACL Launches National Center to Strengthen the Direct Care Workforce

The Administration for Community Living (ACL) has awarded a 5-year grant totaling over \$6 million to establish a national center to expand and strengthen the direct care workforce across the country. This initiative will provide technical assistance to states and service providers and facilitate collaboration with stakeholders to improve recruitment, retention, training, and professional development of the direct care workers who provide the critical services that make it possible for people with disabilities and older adults to live in their own homes and communities.

The center will harness the power of a team of organizations with expertise in disability, aging, and workforce issues, including several organizations that are part of ACL's disability and aging networks. Led by the National Council on Aging, partners include the National Association of Councils on Developmental Disabilities, ADvancing States, Paraprofessional Healthcare Institute (PHI), the University of Minnesota's Institute on Community Integration, the National Alliance for Caregiving, Lincoln University Paula J. Carter Center on Minority Health and Aging, the Green House Project, Social Policy Research Associates, and Housing Innovations.

"The shortage of direct care workers has become a national crisis and a serious civil rights issue," said ACL Acting Administrator Alison Bar-koff. "Increasing numbers of people with disabilities and older adults who want to live in the community – a right protected by the Americans with

Disabilities Act and other civil rights laws – are unable to get the services they need to do so. The Direct Care Workforce Capacity Building Center is an important step toward addressing the challenges to recruiting, training and retention of these critical professionals and creating the robust, stable workforce we need to meet growing needs."

Long-standing workforce shortages have reached crisis levels during the COVID-19 pandemic; today, more than three-quarters of service provid-

The center will harness the power of a team of organizations with expertise in disability, aging, and workforce issues.

ers are not accepting new clients and more than half have cut services as a result of the direct care workforce shortage. High turnover – averaging nearly 44 percent across states – also mean that people who are able to get services often experience service disruptions and receive inconsistent care. As a result, increasing numbers of people are left with no option but to move to nursing homes and other institutions, people who want to leave these facilities cannot, and the health and safety of those who live in the community is at risk. In addition to undermining people's civil right to community living, this leads to poorer health outcomes and higher costs of care, which are most often borne by taxpayers.

With demand for home and community-based services increasing, due in part to the rapidly growing populations of older adults and people with disabilities, more than 1.3 million new jobs for direct care workers will be created by 2030. A coordinated, national effort to improve our national capacity to recruit, train and retain a high-quality, competent, and effective direct care workforce has never been more important.

The national Direct Care Workforce Capacity Building Center will serve as a hub, providing tools, resources and training to assist state systems and service providers and to support the development and coordination of policies and programs that contribute to a stable, robust direct care workforce. The center's website will share resources from the federal government, highlight state and local model policies and best practices that can be replicated or adapted, and share training and technical assistance materials. In addition, the center will facilitate peer-to-peer sharing of lessons learned and promising practices through learning collaboratives and support collaboration between state systems, including Medicaid, aging, disability, and workforce agencies; service providers; and aging, disability and labor stakeholders.

The center will support stakeholders in tackling key issues affecting recruiting and retention, such as:

- Poor wages: According to the Bureau of Labor Statistics, direct care workers were paid a median hourly

wage of \$14.20 in 2021. According to a report from PHI, in 2020, about two in five direct care workers used public assistance programs; a little over a quarter were enrolled in Medicaid and just under a quarter used nutrition assistance programs.

- **Lack of benefits:** According to the same report, in 2020, less than half had health insurance through their employer or a union (and 13 percent had no health insurance at all). Many do not have paid sick days or family/medical leave.

- **Limited opportunities for career advancement and professional recognition.**

The center also will support stakeholders in developing or leveraging existing training and professional development to strengthen the quality of services.

This initiative builds upon the ongoing collaboration to strengthen the direct care workforce between ACL, the Department of Labor, and other HHS agencies, including the Centers for Medicare & Medicaid Services (CMS) and the Assistant Secretary for Planning and Evaluation.

About ACL

The Administration for Community Living was created around the fundamental principle that older adults and people of all ages with disabilities should be able to live where they choose, with the people they choose, and with the ability to participate fully in their communities.

By funding services and supports provided primarily by networks of community-based organizations, and with investments in research, education, and innovation, ACL helps make this principle a reality for millions of Americans.

Military Life

Adults with Special Needs – THE ESSENTIALS

From Military OneSource

Addults with special needs have unique concerns and support requirements. Whether you are looking for support for yourself or you care for an adult with special needs, there are a variety of resources available to address the needs of these adults.

GET ASSISTANCE AT YOUR LOCAL INSTALLATION

Connect with your installation EFMP Family Support provider to learn more about programs and services available at or near your installation. Meet face-to-face with local experts and receive information and referrals to programs, services and needed support to help you manage and adjust through the changes of military life.

EASILY ACCESS SUPPORT SERVICES FROM MILITARY ONESOURCE

A Military OneSource special needs consultant provides free and confidential consultations to help you navigate services for your family and connect you with military and community-based support. They can help you find answers to your questions about finances, support groups, specialized equipment, doctors, Social Security benefits, etc. Consultants can assist with finding independent living options, coordinating with TRICARE Extended Health Care Option and much more. As you prepare to transition or retire from the military, they can discuss state Medicaid waiver programs to help with in-home care or facility care. And best of all, consultants are available 24/7 by live chat or

by calling 800-342-9647. Overseas, check out OCONUS calling options.

BE YOUR OWN BEST ADVOCATE WITH EFMP & ME

EFMP & Me is an online tool designed for military families with special needs. EFMP & Me lets you quickly navigate services, connect with resources and provide support for yourself or your family member with special needs – anytime, anywhere.

Use EFMP & Me from any computer or mobile device and get the information and resources you need at your fingertips. Create your free EFMP & Me account today, customize your checklists and gain access to:

- Information on locating medical and educational resources
- Step-by-step support for EFMP enrollment, PCS preparation, deployment and other military life moments
- Convenient 24/7 access to EFMP resources and services from a range of programs

ADDITIONAL RESOURCES

Relevant Articles

An Overview of Adults With Special Needs
Person-Centered Planning
Military OneSource Consultations
Special Needs Consultations
EFMP & Me Online Tool Empowers Military Families With Special Needs

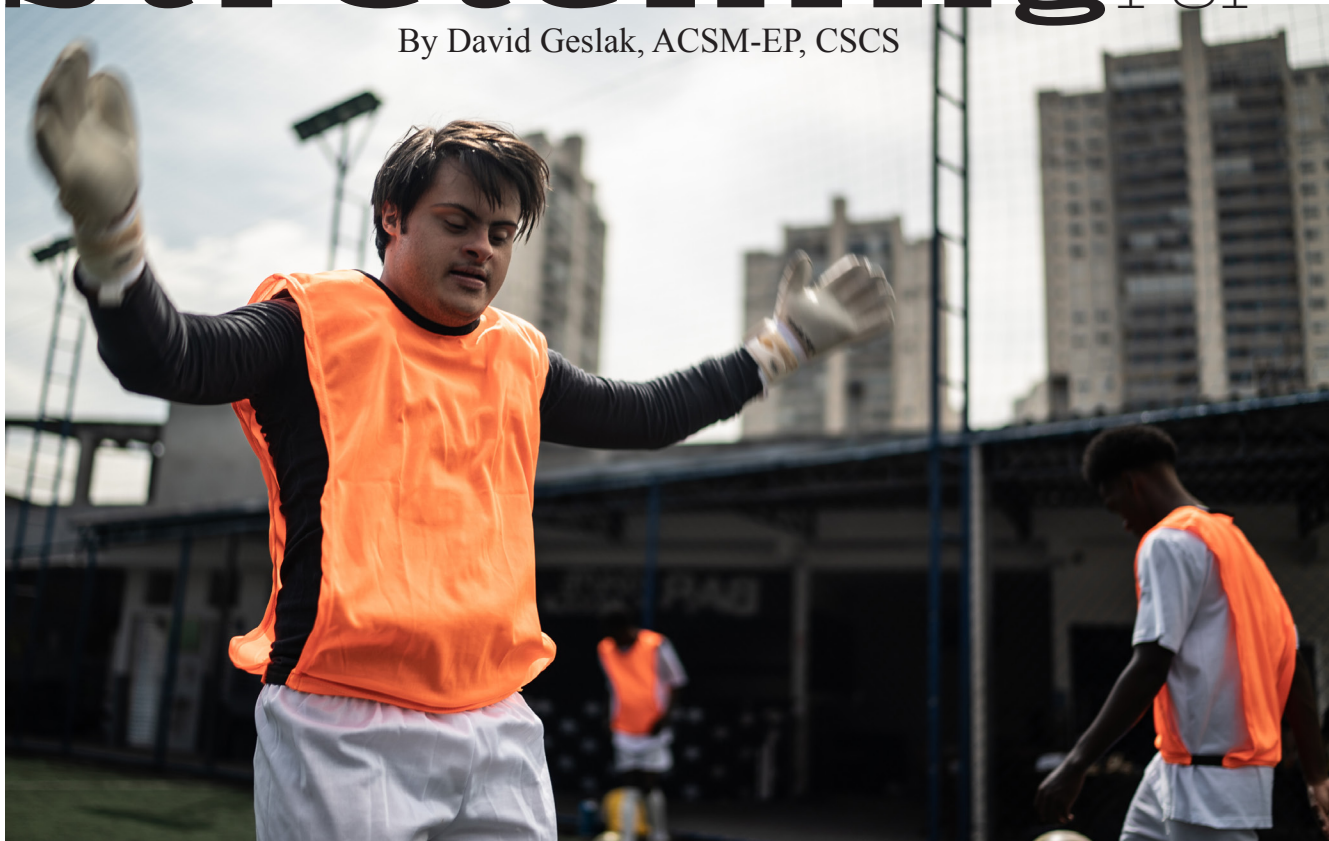
Relevant Resources

Guide for Adults with Special Needs
Special Care Organizational Record for Adults with Special Needs
Establishing the Permanent Dependency of an Incapacitated Child Fact Sheet
Adults with Special Needs eLearning Courses on MilLife Learning
Secondary Dependency – General information
EFMP & Me

(From: MilitaryOneSource.mil)

An Opportunity Worth **Stretching** For

By David Geslak, ACSM-EP, CSCS



As a personal trainer in 2004, I was having a conversation about sports with a father with a 9-year-old son diagnosed on the autism spectrum. With both angst and hesitation, the father asked, “Could you teach my son, Joseph, sports? Also, he can’t skip.” I knew very little about autism. While my undergraduate degree in Health Promotion didn’t include autism, it did teach me about the importance of skipping.

Skipping is a building block to athletic ability and motor planning. I learned that a neurotypical child who can skip, could also read better than a child who could not. I broke down the skipping pattern using the same methodology as when I taught Olympic lifts as an Assistant Strength & Conditioning Coach for the University of Iowa football program.

After four sessions, Joseph was

skipping. His smile was ear-to-ear, his father was wide-eyed, and his mother was crying. Joseph’s family, therapists, and teachers had been trying to teach him to skip for years. As a result of this, two things happened; Joseph and his parents had newfound confidence & optimism, and my career path was forever changed.

Research Meets Reality

After Joseph’s accomplishment, I found many studies that supported unique benefits for people on the autism spectrum. Exercise goes beyond the health-related benefits and can increase desired behaviors (time on task, correct responding), improve language development, improve academics, and decrease inappropriate behaviors (self-aggression, self-injury). While this inspired me even more, I was even more surprised to learn that public schools and the medical

community were not often sharing this with parents. Because of my experience with Joseph and learning this, I felt a responsibility to share the power of exercise. Now I was on a mission.

Many people believe that children get enough physical activity through physical therapy (PT) and occupational therapy (OT). While gross motor and movement-based activities are often part of PT and OT, these services generally do not meet daily physical activity requirements. PT and OT serve a very important function, and I am not suggesting that an exercise program replaces these services. Exercise has its own purpose and is designed to be for a lifetime. PT or OT will end when children’s goals are met, or they “age out.”

Thankfully, the research on exercise for people with disabilities continues to expand and is getting more awareness for its positive impact. In the larg-

est US autism parent survey, Dr. James Adams from the Arizona State University found that autistic parents rated exercise the number one intervention. With that being said, we still have a lot of work to do.

Inventing My “Continued Education”

For three years I continued to train Joseph as well as new clients on the autism spectrum. And the more I did, the more I realized I had to learn. I recognized that if I was going to make a greater impact on this community, I needed to leave the gym. I became a paraeducator at a school for children with autism, Giant Steps (Illinois). While it wasn't listed in my job description, I was changing diapers on 18-year-olds, and being bit, hit, and scratched. There were many days that I wondered if I had made the right decision.

“
Thankfully, the research on exercise for people with disabilities continues to expand and is getting more awareness for its positive impact.”

After a year as a paraeducator, the school asked me to start its first fitness program (kindergarten-transition). As a paraeducator, I had seen students succeed with proven evidence-based tools and protocols in the classroom – but these strategies hadn't made their way into physical activity programs, where they are just as critical. When done properly, the exercise program will be a foundation that will last a lifetime.

For the next 2 years, I gained a tremendous amount of insight from leading this very diverse group of students that I wanted to share with parents, teachers, and professionals. I left the school and started Exercise Connec-

tion. I am proud that my team and I have created three evidence-based and research-supported tools and we have educated and trained parents and professionals in nine countries. We first created the paper-based Visual Exercise System that provides the tools needed to teach fundamental skills, sports, and activities. Then came our Exercise Buddy app, which is supported in seven independent research studies to equip parents and professionals with technology-aided instruction. Finally, to educate professionals and students, we created the Autism Exercise Specialist Certificate in partnership with the American College of Sports Medicine (ACSM). Universities are adopting this Certificate into their curriculums and programs, and we have had students and professionals earn this around the world.

Accomplishing Inclusion Requires a Group Effort

We have learned that our programs are not just empowering the autism community, but many people with disabilities. To truly reach inclusion is going to require a group effort.

Even though the Individuals with Disabilities Education Act (IDEA) and Every Student Succeeds Act (ESSA) support participation in school-based PE, many students with disabilities do not receive appropriate PE services nor access the full benefits from PE. We are going to need policy makers to update and enforce existing policies.

Only 14 states in the United States require an advanced certification for physical educators teaching students with disabilities. That leaves the other 36 states not requiring any specialized training in their undergraduate PE teacher education preparation. We need students to be better educated so when they leave they can be prepared to work with a diverse community.

Finding success with inclusion has been elusive. In the 2018 report, Federal Monitoring and Enforcement of IDEA Compliance, completed by

the National Council on Disability, it stated, “It is disturbing that very little has actually changed since the passage of IDEA more than 40 years ago with regard to the use of monitoring as an effective tool to drive compliance with the law and systemic change that is demonstrated to have an effect on student learning and outcomes.” Parents know this all too well. I am confident that by working together we can do better. We must do better.



David Geslak, ACSM EP-C, CSCS, founder of Exercise Connection, has pioneered award winning & research supported visual exercise tools and programs to improve the lives of those with autism and other disabilities. He is a published author, researcher, and an internationally renowned presenter on autism & exercise. In partnership with the American College of Sports Medicine (ACSM), he created the Autism Exercise Specialist Certificate. In collaboration with the National Center of Health, Physical Activity and Disability (NCHPAD), he created an autism exercise video series that is approaching 1 million views. His commitment and methodology to bringing exercise to those with autism has been enthusiastically embraced by parents, professionals, and higher education around the world. David is an ACSM Certified Exercise Physiologist, NSCA Certified Strength and Conditioning Specialist and has a Bachelor's Degree in Health Promotion from the University of Iowa. In 2022 he was a finalist for IDEA's Fitness Leader of the Year and in 2021 a finalist for ACSM's Certified Professional of the Year.

A Journey Across the Globe

2021-2022

By Dr. Zainab Jamal Algashaamy

My journey of working with people with disabilities started when I was a third-year dental student; after volunteering in the Special Smiles program as part of the Special Olympics World Games that was hosted in the city of Abu Dhabi. While working there, I was taught many lessons that translated into the betterment of my professional and personal life. They have inspired me with their sheer determination, love of life, and desire to go forward, regardless of any obstacle faced. At that moment, I decided to pursue a role that will allow me to participate in improving the quality of life and inclusion in society for what we now refer to as the ones with determination.

After that event, I became an active member of the American Academy of Developmental Medicine and Dentistry (AADMD): University of Sharjah Student Chapter, along with other associations, as the head of the community service. My work and service evolved through the years and came to fruition when I decided to throw my name into the hat to become the president of the AADMD: UOS Student Chapter. After running a successful campaign, we started to heavily encourage every person to be involved in their own capacity as no action is too small to create a change; because we must become the change we believe is necessary in this world. And we succeeded in getting 1500 members to join the AADMD team this year!

The AADMD: UOS student chapter has organized 15 events thus far and is currently planning 3 more during the academic year of 2021-2022. This was the highest number of events per year for the AADMD: UOS student chapter. This



Photo provided by Dr. Zainab Jamal Algashaamy

caliber of participation allowed us to achieve our goals for the year which included: assisting in increasing the quality of life of the determined ones in the UAE specially and the middle east, broadly by providing free dental treatment for those who reside in underserved locations, increasing the awareness of proper management of patients with different types of disability, finally to aid in the inclusion of those with disabilities in the community.

Our year started with a large-scale event where we were able to provide 80 volunteers to the Emirates NBD Unity Run on the 5th of November in 2021. Our objective during the event was to be able to deliver educational information about the determined ones, as well as their parents and care providers. To achieve this task, we deployed two of our mobile clinics:

1) The Mobile Dental Clinic of the University of Sharjah, which is composed of 3 dental units fully equipped with all necessary materials for oral health screening, as well as simple procedures such as fluoride application with the ability to refer the necessary cases to the University Dental Hospital in Sharjah for treatment. Each dental unit

had two student dentists and nurses to perform the examination supervised by our staff dentist Dr. Shadi Al Khatib and 2) The Mobile Medical Clinic of the University of Sharjah, for blood sugar level, blood pressure screening, and an eye test performed by medical students and supervised by a staff physician. Following the success of the event, we were able to participate in the same capacity in the Dubai Investments Green Run and Walk For Awareness by Access Ability Expo.

One of our largest events of the year was in collaboration with the Special Olympics, organizing the Special Smiles program to screen and treat athletes of the national team of the UAE in the mobile dental clinic while raising awareness about the importance of preventative oral health.

In a first-of-its-kind event for the AADMD: UOS Students Chapter, we have organized a

patient education, foster cultural exchange, and expand the skills and horizons of the volunteers.

The program consisted of a 5 days medical camp where the volunteers were divided into teams of medical doctors and dentists. The dental team practiced scaling, extractions, and denture fabrications, while the medical team performed physical examinations and drug distribution. The remaining 2 days were designated for sightseeing and enjoying the beautiful country of Nepal.

In order to further the communication with and inclusivity of the determined ones with the community and health care workers, we hosted a sign language workshop on the 9th of November 2021 with a total of 50 attendees.

We hosted multiple visits to multiple centers in the UAE, starting with the virtual campaign With Al Noor Training Center for Persons with Disabilities and physical visits to Pulse Center and Manzil Center, which were done on a weekly basis. These visits included medical and dental checkups, teaching the children about oral health as well as creating the environment for both the volunteers and children to enjoy their time during organized and goal-oriented play sessions.

We also hosted exhibitions in AIESEC Middle East and Africa Youth Speak Forum 2021, the Dubai Accessible Tourism

International Summit, The International Conference of Pharmacy & Exhibition, and 1st Mena Conference for Rare Diseases Hybrid Conference, in order to increase the reach and

exposure of AADMD within the UAE and middle east and to introduce the concept to the community of the UAE to further our goals of inclusion and breaking barriers.

Finally, we founded the AADMD book club to raise awareness among AADMD participants by reading a book written by or about a person with a disability. The members of the book club would later discuss the book, thereby allowing them to gain more insight into the experience of life through the eyes of people with disabilities.

I hope that the AADMD's extension into the MENA region, as well as the work of my team, will be a step that will be continued by those to whom we will pass on the baton, in order to continue improving quality of life of those with disabilities in the region, foster further inclusion in society, and finally a better understanding for the health care professionals who have the responsibility of caring for them. I would like to thank my board of governors, whose efforts allowed the successes of this year to be possible, starting with Dr. Shadi, the association founder and adviser, and my beloved board members Alaa, Alaa, Abdulkader, Abdulrahman, Khadijah, Lina, Linah, Maryam and Zumurd who made this year even better.

Dr. Zainab Jamal Algashaamy, President of the American Academy of Developmental Medicine & Dentistry: University of Sharjah Student Chapter. He is a dental intern at the University of Sharjah Dental Hospital who graduated last July with "excellency with honors". He is also the president of the American Academy of Developmental Medicine and Dentistry: UoS Student chapter 2021-2022. Website: www.aadmduos.com Instagram: #aadmduos



Photo provided by Dr. Zainab Jamal Algashaamy

volunteering trip to Nepal with 25 young dentists, doctors, and medical and dental students who all met in Nepal for one goal, which is to increase

Unlocking Behaviors: A “Simple” Introduction

By Craig Escudé, MD with Ley Linder, MA, M.Ed, BCBA

“

When we understand that behavior is a form of communication, we learn that the person was never suffering in silence. We just didn't understand what their behavior was communicating.

Behaviors. We all have them. When we hear the term “behaviors” used in reference to people with intellectual and developmental disabilities, it is usually used to refer to some sort of adverse behavior that is disruptive or dangerous to the person, or a challenge for people who support that person in their life. Understanding what a particular behavior might mean can be the difference between someone getting the help they need and suffering needlessly in so-called silence, sometimes for years. When we understand that behavior is a form of communication, we learn that the person was never suffering in silence. We just didn't understand what their behavior was communicating.

In this series of articles, you will be presented with a case related to some sort of behavioral issue, followed by a discussion from a medical perspective and from a behavioral analysis perspective. The idea is to help you think outside the box to avoid the infamous trap of “this is just what they've always done.” There is a high likelihood that most of us have fallen into this type of thinking, which is a form of diagnostic overshadowing, at some time or another during our careers. Diagnostic overshadowing is when a new behavior or symptom is attributed to the person's intellectual or developmental disability rather than looking for a treatable underlying cause. It was the subject of the June 22, 2022, Sentinel Event Alert from The Joint Commission. It's a document certainly worth reading.

Let's start with one of the most memorable cases of my career.

History

John was a 32-year-old man with a severe intellectual disability who ambulated, could feed himself, needed assistance getting dressed, used the bathroom independently, and did not use words to communicate. There was a new physician who was on his first day at our residential program who was asked to take a look at John because of a new onset of a limp. Upon questioning staff, the limp started that morning when he got up from bed. There was no report of any injury in the preceding hours or days.

Exam

John's shoes and pants were moved, and there was no evidence of any bruising, swelling, or apparent tenderness with passive or active movement of his hip, knee or ankle. Basically, he had a completely normal exam.

Tests

The new-to-the-job physician ordered an x-ray of the hip, knee, and ankle to look for any possible bone or joint issue that could be causing the limp.

Consultation

Being the "seasoned" "brilliant" clinician that I was, (hope you are chuckling) I offered one more "examination" for the new doctor to consider. "Let's take a look at his shoe."

Inside of John's shoe was a balled-up sock. I performed an emergency "sockectomy," and John was miraculously cured of his limp.

Discussion

The moral of the story is "Think Simple First!" Many times, people

who do not use words to communicate cannot express things that are quite simple to resolve: pants being too tight causing abdominal pain, resisting wearing an orthotic or CPAP mask because it is ill-fitting, and the like. Think about the simple causes of agitation, behavior changes, or clinical symptoms first and rule them out. Then we can move on to X-rays, CT scans, labs, and other tests and examinations. Plus, if you are the one to figure it out, it can make you look like a genius!

Hope you enjoyed this first "simple" case. The others won't likely be quite so entertaining, but hopefully, they'll help to broaden the differential diagnosis for particular behavioral issues and will increase clinical accuracy. My friend Ley Linder M.A, M. Ed., BCBA will be joining me in this series so you'll get both a medical and behavioral perspective on future cases.

Until next time, "behavior" self!

Dr. Craig Escudé is a board-certified Fellow of the American Academy of Family Physicians and the American Academy of Developmental Medicine and is the President of IntellectAbility. He has more than 20 years of clinical experience providing medical care for people with IDD and complex medical and mental health conditions serving as medical director of Hudspeth Regional Center in Mississippi for most of that time. While there, he founded DETECT, the Developmental Evaluation, Training, and Educational Consultative Team of Mississippi. He is the author of "Clinical Pearls in IDD Healthcare" and developer of the "Curriculum in IDD Healthcare", an eLearning course used to train clinicians on the fundamentals of healthcare for people with IDD.

Ley Linder, MA, M.Ed, BCBA is a Board-Certified Behavior Analyst with an academic and professional background in gerontology and applied behavior analysis. Ley's specialties include behavioral gerontology and the behavioral presentations of neurocognitive disorders, in addition to working with high-management behavioral needs for dually diagnosed persons with intellectual disabilities and mental illness. He is an officer on the Board of Directors for the National Task Group on Intellectual Disabilities and Dementia Practices, works closely with national organizations such as the National Down Syndrome Society, and is the owner/operator of Crescent Behavioral Health Services based in Columbia, SC.



This is what we saw inside John's shoe.

The Firestorm of Rare Epilepsy:

Our Girl's Dreamless Nights

By Luke Rosen

Susannah does not wear pajamas to bed, she wears battle gear. After her bath is finished, teeth brushed, stories read and songs sang, it is time for the grueling marathon that is Susannah's rare, nocturnal epilepsy. Her nine-year-old brother, Nat, flies into the bedroom like Superman and hugs her tight. "Night Shasha!"

Before he flies back upstairs to save the world, Nat asks which one of us will sleep with Susannah tonight. We answer with a smile. Our remarkable son is too kind to ever let on, but we see it in his eyes. He would do anything to have both parents to himself just for one night.

And he's off.

I kiss Susannah, tell her I am proud of everything she does, and that I love her too much to even say. Sally softly sings again, and we wait anxiously as Susannah's heavy brown eyes fall closed. And like that, our little girl is off to battle. When Susannah falls asleep she does not journey into

dreams of Rapunzel's tower or Elsa's castle. Instead, her brain slips into a nightly firestorm of continuous spikes, waves and seizure-like activity. A neurological nightmare that some children never wake up from. For the next ten hours our girl's life is extremely fragile.

When Susannah was diagnosed in 2016, she was the only person known

to have a rare neurodegenerative disease caused by one specific mutation (P305L) in the KIF1A gene. KIF1A is responsible for making a protein

which is vital for brain function. Our daughter's genetic anomaly triggers a constellation of medical complexities: movement disorder, cortical vision impairment, spasticity, brain atrophy, and epilepsy. At the age of two, she was diagnosed with a very rare form of epilepsy called Electrical Status Epilepticus in Sleep, or ESES. The

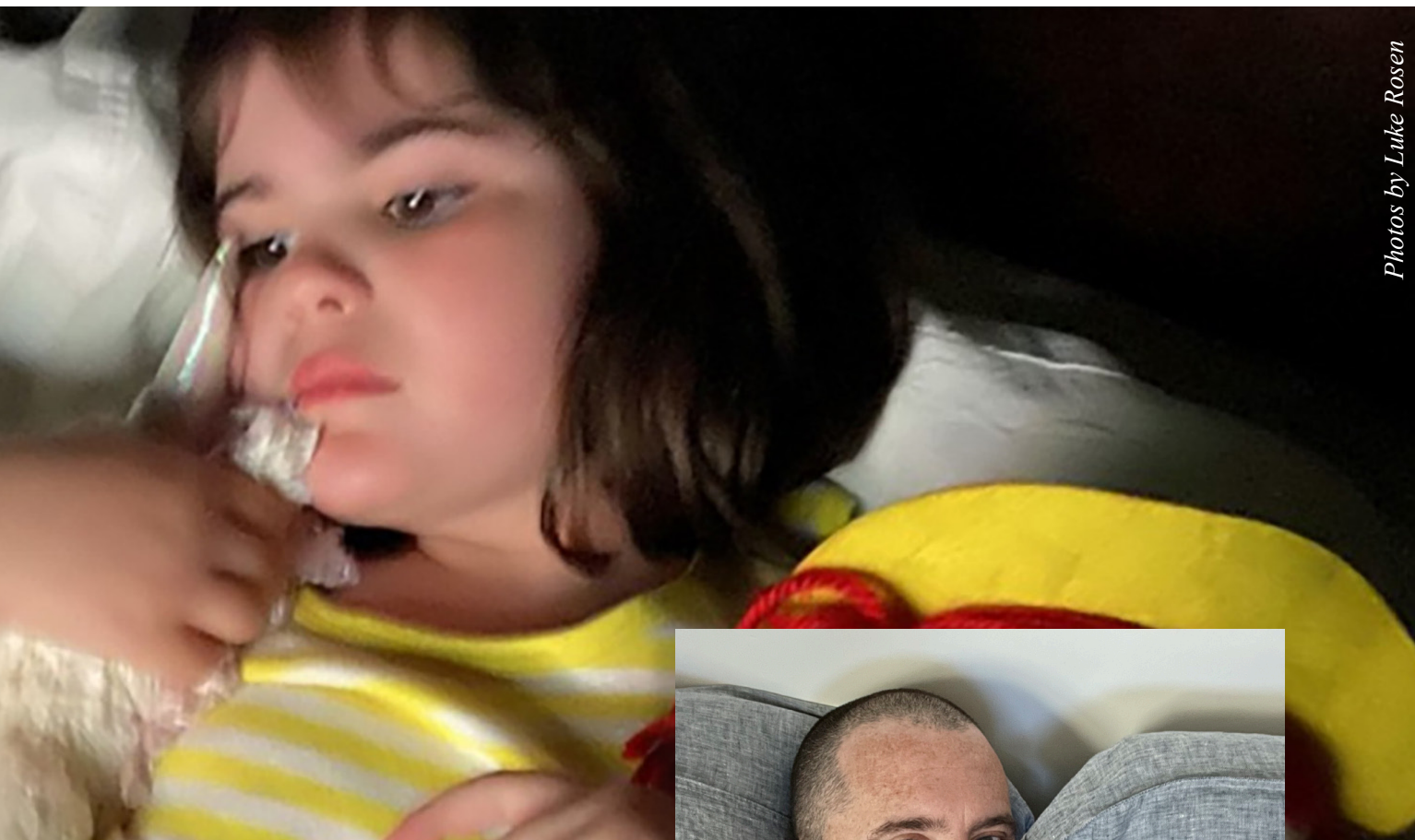
““ We watch her sleep, waiting for that match to strike and ignite a blaze.

severity of ESES is measured by percentage of seizure activity, or continuous electrical discharges in the brain captured only by EEG during sleep. At last count, 100% of Susannah's sleep was filled with epileptic discharges. She has different types of seizures during the day, but this nocturnal epilepsy prevents Susannah from ever reaching the most crucial stage of sleep: REM.

Susannah's epileptic encephalopathy is kindling to a potential forest fire in her brain. We watch her

sleep, waiting for that match to strike and ignite a blaze. She twitches, and sweats like a marathoner throughout the night. Susannah's breathing slows. Sometimes I wake her just to make sure those breaths have not slowed to a stop. Still, the most damaging outcome of these epileptic spikes in her brain is a complete lack restorative





sleep. REM sleep is vital for brain development. It is that deep, wonderful sleep which yields recovery and alertness. REM is the stage of sleep when critical areas of the brain are stimulated. This sleep is responsible for skills like learning, memory, movement, energy and cognition. The REM stage of sleep is when we dream. Susannah never gets there.

KIF1A steals away steps, words and vision. These are measurable deficits, painful reminders that her disease is progressive - but tangible. We can count words and steps. We know when Susannah's sight fails. Dreams, however, are magical and intangible events; intimate worlds far too complex to capture or describe in detail. Dreams are deliciously ambiguous, private secrets that inspire action. Is Susannah's disease so ruthless that it robs children of the ability to dream too?

It is hard to describe the flood of panic when a doctor explained possible consequences associated with ESES, and lack of REM sleep: deteriorating neurons, dementia, loss of motor skills and speech. But Sally and I have heard it before. These outcomes are similar to the implications associated with her genetic condition. To fathom this future for any child is impossible, but the epilepsy part of her decline can be prevented if we dampen the fire inside Susannah's sleeping brain.

Is it possible to address the severity of KIF1A Associated Neurological Disorder if we control the catastrophic



Luke Rosen with his daughter Susannah

seizure activity in Susannah's sleep? If we race to find an effective medicine for her epilepsy, maybe we can slow the clock - a bandaid to buy her more time. Epilepsy is just one piece of her rare genetic disease. The seizure symptom of KIF1A compounds everything, and makes life so hard. Every hour of every day Susannah's brain and body run on fumes because her nights are filled with epileptic firestorms. The tank empties more with every dreamless night, and fatigue triggers severity in every aspect of her health: balance, vision, focus, speech, energy, spasticity, more seizures. All parts of KIF1A made worse by ESES. In the morning, after her marathon of spikes and waves, acute battle fatigue sets in, and it is our job to activate the neurons in Susannah's brain and get her body moving.

The list of medical emergencies is not what makes me cry after her brown eyes close at night. What continuously breaks my heart is that I know Susannah's disease prevents her from having dreams. Our daughter never gets to dream; never gets to wake up with that carefree feeling of returning from an indescribable magical journey of dreams filled with flying unicorns. Instead of "sweet dreams" we kiss Susannah on the forehead, tell her we love her, smile with deceptive confidence and tuck her in. We sing her to sleep, then she closes her eyes and goes through hell.

Like most parents, if I had one wish, it would be for my children's dreams to come true. When my son wakes up, I ask him what he dreamed about. Some mornings it was playing second base in the big leagues, and other mornings he describes buildings he designed, and his dream to be an architect - or a superhero jumping from those buildings to save people. It is so beautiful to hear him unpack those dreams. When I ask Susannah what she dreamed about last night, we have a fleeting moment of hope, a sliver of hope that today she will rattle off whatever dreams may have come the night before. Instead, she looks at me with glassy round eyes and smiles. A pause before she works hard to find words; words that once were easier for her to recall. I hug her tight.

If there was one magic pill, a pill that could cure only one of the myriad challenges our sweet girl lives with, what would it be? If only one part of her devastating disease could be treated, what would I choose? I would not choose a pill to help her walk or see. If there was only one part of this damn disease that we could cure, I would choose a magic pill that gives Susannah the chance to dream. I would do anything for our girl to describe vivid dreams



Susannah and her mother, Sally



Our daughter never gets to dream; never gets to wake up with that carefree feeling of returning from an indescribable magical journey of dreams filled with flying unicorns.



Susannah and her brother, Nat

with enigmatic endings. Tales of running through castles and losing herself during a night of perfect sleep. I would be so lucky to appear as a character holding Susannah's hand in the dreams she decides to share with us. Soon.

We work with doctors to find the right combination of medications, hoping for a temporary fix. With every EEG comes a new drug. A medicated rollercoaster of side effects in a monogenetic nightmare where clarity was fleeting long before we titrated up on the last benzodiazepine. We need new treatments today. Not tomorrow, not in one year or ten years. If we wait any longer nothing will come in time to help Susannah and kids like her. We are trying. It is a costly, life-altering burden to drive rare disease research — research which might go away if the lemonade stands stop and the funds run out. We need help to develop treatment before the damage is beyond repair. We need treatment that slows degeneration and makes Susannah's life less severe.

Last night I was home alone with the kids for the first time in months. Sally was returning well after bedtime, so it was my night to sleep with Susannah. Nat asked if he could sleep in his sister's bed, and Susannah sharply replied with a yell "slumber party!" The three of us climbed in, watched a movie and they fell asleep. Bliss. I slipped out of bed and went into the kitchen to begin tomorrow's prep. Sally walked through the door a few hours later, and we found ourselves in the rarest of moments. It was nighttime. We were alone. Together. Rare because one of us always sleeps with Susannah while the other prepares for the chaos of tomorrow's remote learning, therapies and work. It felt strange to be alone with my wife, but we took advantage of the moment and sat down to talk. We

spoke like two people who had not talked in years, even though we are together more these days than ever before. During the last ten months we rarely see each other after the kids bedtime. Even with this tiny escape from routine, something felt off. We sat on the couch eating ice cream when Nat's terrified voice called from the bedroom, "Dad get in here! Somethings wrong with Sus!" Snap back to reality. Sprint into the room.

Susannah was lying asleep covered in her own vomit and gurgling. Without hesitation, Sally picked her up, cleared the vomit from her mouth and Susannah woke up. She was in a midnight haze, weary from her march through the battlefield of seizure-filled sleep. Thanks to Nat's slumber party and awareness, his sister did not aspirate or stop breathing last night.

Some nights Nat and I read Shakespeare after Susannah and Sally are in bed. I use funny voices, and he asks to hear the battle scenes again. Last week we read Macbeth. I thought of Susannah downstairs fighting an invisible enemy in her dreamless sleep. I read Macbeth's lines:

Innocent sleep. Sleep that soothes away all our worries. Sleep that puts each day to rest. Sleep that relieves the weary laborer and heals hurt minds. Sleep, the main course in life's feast, and the most nourishing.

In that moment, four years after her diagnosis, I understood Electric Status Epilepticus in Sleep. The impact of Susannah's epilepsy was clear to me. As described by Shakespeare, Susannah's rare epilepsy prevents sleep from healing her hurt mind; a mind hurt with atrophy caused by a rare and toxic genetic mutation in KIF1A.

No doctor explained ESES in this logical way. No medical journal educated me about Susannah's specific form of epilepsy. Lying in bed, reading Macbeth to Nat in a funny voice, I finally understood our daughter's epilepsy. Shakespeare explains the mechanism of Susannah's disease



with far more clarity than any neurologist. I read the lines again, Sleep that relieves the weary laborer and heals hurt minds. Sleep, the main course in life's feast, and the most nourishing.

I looked at Nat, smiled and turned off the light. I was covered with a rare blanket of comfort, an overwhelming feeling that tonight Susannah will win the battle. Tonight Susannah will dream, and tomorrow she will tell me all about it. In her own way.

This article is included in the upcoming monograph "Sleep and Sleep Disorders in People with Disabilities" published by HELEN: The Journal of Human Exceptionality.

Luke Rosen and Sally Jackson founded KIF1A.ORG in 2016 following their daughter Susannah's KIF1A diagnosis. In 2017, Luke left his career in film and television to accelerate discovery of treatment for Susannah and children like her.

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ABOUT KIF1A.ORG

KIF1A.ORG is a global community dedicated to improving the lives of those affected by KIF1A Associated Neurological Disorder and accelerating research to find a cure.

KIF1A is a molecular motor protein vital to brain function. Mutations in KIF1A cause a severe neurodegenerative disorder with a progressive course. The disease is associated with:

- Cognitive impairment
- Cerebellar atrophy
- Ataxia
- Spastic paraplegia
- Hypotonia
- Epilepsy
- Optic nerve atrophy
- Peripheral neuropathy

KIF1A Associated Neurological Disorder is a new disease, and research is rapidly underway to discover treatment. Every day we are closer to understanding KIF1A and how brain function is disrupted by mutations in the gene. Accelerating this research will lead to rapid development of medicine. Time is as much our enemy as nature. We urgently need your support to save the lives of children affected by KIF1A.

OUR VISION

Our goal is clear: to immediately find treatment for every individual living with KIF1A Associated Neurological Disorder. We dream of a world with an easily accessible cure for our kids with KAND.



A Musical

Revolution



Martha Summa-Chadwick calls it her “hair-on-the-back-of-the-neck moment.”

A pianist by profession and music therapist by passion, she was working with an autistic 4-year-old girl who had never spoken. The work was agonizingly slow at first.

After discovering that the girl was fascinated with computers, Summa-Chadwick—who has spent most of her paycheck-earning career as a computer specialist—turned to a software program with lessons on how to read music.

“It took a while but, when it took, it took off all of a sudden. She got it,” recalls Summa-Chadwick, who was teaching piano at University of Tennessee at Chattanooga at the time. “We plugged in the keyboard, and she started playing right away.

“And then she started singing.”

Such enormous breakthroughs are not the everyday results of music therapy. Mostly they’re incremental steps that lead to small successes that build upon each other. Since starting in the early 2000s, Summa-Chadwick has used music therapy to help those suffering not only from the mental and emotional effects of autism but also the physical effects of Parkinson’s disease, cerebral palsy and strokes.

It has not been an easy path to walk, she says. Not everyone—including some doctors—believes music therapy is beneficial or even works at all.

By Shawn Ryan

Photos by Angela Foster,
University of Tennessee at Chattanooga photographer



“Over 20 years of advocacy, there have been many times when I’ve said, ‘I’m done. I’m not doing this. I’m tired of getting doors slammed in my face. I’m tired of people walking away and saying, ‘No, this isn’t worth it.’ Then the next day I stand up and say, ‘It’s too important.’”

“I truly, truly believe that music can revolutionize health care and education if we would only go there, and I have to carry that message.”

Neurological studies have shown that music therapy works, but the word isn’t getting out enough, she says.

“There’s gobs of neurosciences up there. It’s staying up there in neuroscience land. It’s not filtering down. That’s where the groundswell coming up from public opinion needs to happen.”

Jumpstarting public opinion is one of the biggest hurdles, though. They may hear the phrase, but most people often don’t know what music therapy actually is, says Summa-Chadwick, who earned a master’s degree in music in 1996 from UTC.

“The person on the street thinks that the musician playing over in the hospital is doing music therapy,” she says.

She’s doing her part to spread the word through such avenues as Ted Talks presentations, educational videos and published articles. She was chosen as a 2022 Honored Artist of the American Prize, a national nonprofit that describes itself as the nation’s most comprehensive series of contests in the classical arts. The Honored Arts award goes to individuals and ensembles that have shown outstanding creative or intellectual achievements. In Summa-Chadwick’s case, the award is for her advocacy of music as medicine.

Since 2013, she also has hosted the Power of Music concerts, annual performances that—along with a range of

music that stretches across classical, jazz, blues, opera and pop, among others—feature panel discussions on the therapeutic outcomes of music therapy. The concerts are presented by Music Therapy Gateway in Communications, a nonprofit founded in 2013 by Summa-Chadwick, who remains its executive director.

Music therapy can work on multiple levels and improve multiple issues, she says, by increasing the brain’s plasticity, the condition of creating new neural pathways when others are damaged.

Walking, for instance, can be a serious issue for those with brain dysfunction. Music can help alleviate some of those problems, Summa-Chadwick says.

The number of steps a person takes usually corresponds to the number of heartbeats per minute, she explains, so improvement means increasing or decreasing the music’s tempo to match the steps.

Brain damage caused by a stroke may mean a walking tempo of 60 beats per minute, almost slow motion. People with Parkinson’s take a lot of short steps to offset balance issues. Children on the autism spectrum walk in a “kinetic stutter,” she says.

“After a person has a stroke, you want to gradually bring them up so they’re walking faster. A person with Parkinson’s, who’s walking a lot, you want to slow that down, let them take longer steps.”

“With the children with autism, a lot of times, the goal is just to get the gait stronger, specifically, walking on the beat.”

It may seem obvious, but a key factor in music therapy is finding the right type of music, whether it’s rock, jazz, classical, whatever, she says. For the best results, the music must have a personal relevance to the person. As an example, an older person with dementia may like the Beatles or Frank Sinatra, she says.

“Research shows that the music they’re going to prefer is what was

happening in their formative years of high school or college,” she says.

On the other side of the age range, one of her young patients loved “Happy Birthday to You,” so she started therapy with it.

Things get tough if the patient is nonverbal.

“If they can’t communicate it, then it’s a best guess,” she says.

Sometimes those guesses don’t hit the right note.

“I remember there was a 5-year-old I was working with, and I thought every kid wanted ‘Wheels on the Bus,’ so I played ‘Wheels on the Bus.’”

“He did really well for a while and then gradually he wasn’t doing as well. His mother said, ‘Would you play some Beethoven? He hates ‘Wheels on the Bus.’”



(Published with Permission from Our Tennessee, the magazine of the University of Tennessee system.)

Shawn Ryan writes for Our Tennessee magazine.

myFace

Changing Faces, Transforming Lives, and Ensuring No One with a Facial Difference Ever Feels Alone

By Katie Bazyluk

Every hour a child is born in the United States with a craniofacial condition, which begins a unique physical and emotional journey for both the child and their family. About 95% of these babies will undergo multiple surgeries and endure long-term medical care throughout their childhood and into their adult lives. Ad-

ditionally, the faces of another 100,000 individuals are altered through accident or disease each year. The goal of myFace, a non-profit organization based in New York City, is to be able to reach and support all of them.

For those who aren't familiar, a craniofacial difference is any anomaly affecting one's facial structure and skull. Facial

differences can affect more than one's physical appearance - they can impede the basic functions essential to survive, such as breathing, hearing and eating. Individuals with a facial difference - and their families - not only have to deal with the physical effects of their condition, but the challenging emotional impact as well, as they are often subjected to bullying and made to feel "less than" or "othered" by stares and rude remarks.

myFace, formerly the National Foundation for Facial Reconstruction (NFFR), was founded in 1951, under the leadership of pioneer Plastic Surgeon Dr. John M. Converse, to address the visible and invisible challenges of living with a facial difference. The organization's mission was to support state-of-the-art treatment for children, conduct innovative research, and provide medical training to inspire future generations of doctors. As the decades progressed, myFace recognized the importance of focusing holistically on the entire journey, encompassing both the physical and emotional, and everything in between. A cornerstone of myFace's work today is also to raise awareness about craniofacial conditions, and address the obstacles that people with facial differences overcome on a daily basis.

At the heart of myFace's approach are three pillars of support:

- **Grant Funding:** myFace provides grant funding to top-quality craniofacial centers across the country to ensure that patients are able to receive medical, dental/orthodontic care, and psychosocial care regardless of their ability to pay. This flagship work takes place at the myFace Center for Craniofacial Care at NYU Langone Health in New York City.

- **Direct Services:** myFace seeks to meet the day-to-day needs of individuals with craniofacial conditions through Support Groups that foster community and provide an environment where participants can feel safe, hopeful, and know they are not alone. Free and accessible accommodation and travel are delivered through a transportation grant



myFace Director of Family Programming, Dina Zuckerberg (second from left), pictured with several myFace Stars at the annual myFace Celebrates talent show in May 2022.

program and myFace Family Apartments, enabling patients to receive treatment in New York City. myFace also partners with Craniofacial Centers across the country to deliver free Newborn Craniofacial Care Kits that enable low-income families to adequately support their little one in their first months of life.

- Public Awareness and Education: myFace seeks to educate patients,



“Building understanding leads to empathy, and empathy changes society for the better.”

families, and healthcare providers across the country through the Transforming Lives Webinar Series; and raise public awareness through the Wonder Project school assemblies, and monthly myFace, myStory: Voices from the Craniofacial Community podcast, where individuals can share their stories, be seen, and be heard.

“A central part of our mission is to raise awareness of the craniofacial community to the general popula-

tion, and help them understand what individuals with facial differences and their families confront,” says Stephanie Paul, myFace Executive Director. “Building understanding leads to empathy, and empathy changes society for the better.”

myFace also hosts annual events where patients and families have the opportunity to meet one another and create an extensive community support system, such as myFace Celebrates, a special talent show that highlights the abilities of young people in the community, and Races for Faces, a 5k walk and carnival that brings together a diverse community to advocate for and celebrate those with facial differences.

myFace community member Alyse can attest to the real difference that myFace makes in the lives of individuals with facial differences. At the age of 2, Alyse was diagnosed with rhabdomyosarcoma, a form of soft tissue cancer. Though the chemother-

apy and radiation she underwent were successful in treating her cancer, the radiation affected the soft tissue and normal development of her facial bones, jaw and teeth – requiring close to a dozen surgeries over many years to reconstruct her face. As she grew up, Alyse and her family had little to no social support or resources - there was no “myFace” that she knew of to



myFace community member Alyse, an active participant in the adult support group.

provide the resources and necessary tools to support them through her journey. In May 2020, however, she came across a post in a Facebook group for those with facial differences, and was inspired to reach out to myFace.

Ever since, Alyse has been an active member of myFace’s Adult Support Group, and is grateful to finally be able to connect with others who “simply understand what it’s like,” and draw strength from shared experiences.

“Connecting and sharing experiences with others can bring a great amount of importance, meaning, and support into the lives of so many individuals and families. By being a part of the myFace community, I hope to make an impact and serve as an additional support for others living with a craniofacial difference,” she shares.

With a spectrum of programs, direct services, annual community events, and partnerships with craniofacial centers across the country, myFace is uniquely positioned to bridge the gap between the medical and emotional aspects of a craniofacial patient’s journey. myFace aims to ensure that children and adults with facial differences across the country - as well as their families - feel understood and appreciated in their uniqueness, and know that they are never alone.

To learn more about myFace, visit www.myFace.org.



A myFace family at the 10th Annual Races for Faces celebration held in New York City in September 2022.



By Theo Karantsalis

A rainstorm hid my tears, after trial, as I hobbled in a walker onto a train where a wet floor launched me into the metal handrail with each abrupt stop.

My prisms for double vision stored an iridescent glare of the Dolce and Gabbana belt buckle worn by opposing counsel who earlier underscored that I had filed 70 court cases.

One of those cases was now before the presiding chief federal judge, a former county judge, who oversaw a case I tried 27 years ago against an immigration union.

Judges were fond of the offbeat librarian, a chatterbox who shelved books at the courthouse law library, worked on election campaigns, and earnestly litigated claims against big companies for as little as \$5.

Some cases sought unusual injunctive relief, like one against a company that refused to publish *What most*

attorneys are good for, an “unabridged treatise” with blank pages. That case was resolved through mediation after both parties agreed the book would have one word: “nothing.”

A Stanford psychiatrist hired by my employer, the U.S. Justice Dept.,



Those with brain and mind disorders who go it alone against big law firms are easily kicked to the curb cut.

deemed me unfit for duty after my home was raided by agents who seized five guns, a passport and about \$3 in change. Erratic behavior and three restraining orders led to a deal and a non-stop drive in a Ford Ranger from San Francisco to Miami.

Aside from brain lesions that affect

vision and mobility, due to multiple sclerosis, the federal court heard about psoriatic arthritis, a disease that causes joint swelling and bloody skin lesions.

Schizoaffective disorder, a combination of schizophrenia and bipolar, causes delusions, hallucinations, and thought disturbances, and mega-doses of mood stabilizers, anti-psychotics, and anti-depressants keep me tethered to earth.

Police escorted me out of the community college library, three years ago, after being served with termination papers. The next few months were spent in isolation, mostly in a shower stall where I squeezed paper towels and ran the faucet.

Water has always provided an escape, like the time I was chased by Oakland cops, as a youth, and dove



nude from a bar and swam across an estuary.

Now a frail senior, the only waves I make are at the city pool. Though getting there meant pushing a walker or wheelchair from our driveway into traffic, as the corner lacked a sidewalk and curb cut.

Fewer than one percent of disability cases make it to trial, as mine did.

A judge initially tossed the case, pointed to my 2008 filing and ruled that I lacked standing. One of the nation's best civil rights attorneys stepped in, appealed, and argued that my disability progressively got worse and that I had secured standing, well, when I was no longer able to stand.

"This is because, taking the facts in the light most favorable to Karantsalis, in which his injuries started in 2017 instead of 2008, he brought his claim forward within the relevant statute of limitations and thus "raise[d] a right to relief above the speculative level"

at that time," an appellate court said in the precedent-setting decision.

However, my three-square-mile city with 10 churches, population 13,869, that sits north of Miami International Airport, chose to fight rather than fix.

Shortly before trial, some issues in the complaint were hastily addressed as tractors revved and blew diesel as a last-ditch effort by the city to bulldoze, or moot, the case, a strategy that leaves no live dispute for a court to



Equal access for society's weakest members can only be achieved if the people fighting on their behalf have the courage, big gloves, and irons jaws to go the distance.

resolve.

Concrete dust hovered above my corner as feral contractors in orange vests pounded and poured a new curb cut. More dust followed, days later, when they ripped and re-poured because they measured the slope wrong.

On the eve of trial, a Sunday, an accessible public parking space was painted at City Hall, leaving a few remaining claims. When the judge ruled in favor of the city on those claims, I lowered my head. As a US Marshal saw me out, I pondered:

- how painting a blue curb near the police substation and a U.S. Post Office poses a safety hazard,

- why a popular picnic park, where families often park and watch alligators, does not require accessible parking,

- whether taxpayers care about footing the bill for a Pyrrhic victory stemming from years of costly and unnecessary litigation.

This journey illustrates why pro bono clinics like Davie-based Nova Southeastern University's Adults with Intellectual & Developmental Disabilities office, which represented me through three terrific law professors, Matthew Dietz, Leigh Markowitz and Talhia Rangel, warrant public applause and substantial funding.

Those with brain and mind disorders who go it alone against big law firms are easily kicked to the curb cut. An underdog's battle for justice versus billable-hours machinations requires, as Teddy Roosevelt said, getting one's face marred by dust and sweat and blood.

Equal access for society's weakest members can only be achieved if

the people fighting on their behalf have the courage, big gloves, and irons jaws to go the distance.

Because change comes about by staying in the ring.

"Going in one more round when you don't think you can, that's what makes all the difference in your life." - Rocky Balboa

Freelancer Theo Karantsalis is a San Francisco native who lovingly served Miami's Black community for many years as an offbeat librarian. He speaks softly and carries a big pen. Website: litwithfire.com

Politicians with Disabilities



Rhode Island Congressman Jim Langevin (second from right) joins colleagues to celebrate Rhode Island College's Paul V. Sherlock Center on Disabilities as they renew their status as a University Center for Excellence in Developmental Disabilities. Rep. Langevin is the first quadriplegic to serve in the U.S. House of Representatives.

By H. Barry Waldman, DDS, MPH, PhD, Rick Rader, MD, FAAIDD, FAADM,
Steven P. Perlman, DDS, MScD, DHL (Hon), Allen Wong, DDS, EdD, DABSCD

"...researchers find an estimated **10.3 percent of elected officials serving in federal, state, and local government - a total of nearly 3,800 people - have disabilities. That is more than five percentage points lower than the overall disability rate in the adult population, suggesting that people with disabilities are underrepresented in the halls of power.** (emphasis added) However, the report finds three notable exceptions: younger people with disabilities, Native Americans with disabilities, and disabled veterans of recent wars are well-represented in politics."¹

Raw Numbers

An estimated 3,793 of the 36,779 elected officials in the U.S. have a disability

Bright Spot

Three subgroups are well-represented: people with disabilities ages 18-34, Native Americans with disabilities, and veterans with disabilities from the Gulf War to the present (including those who served in Iraq and Afghanistan).

Big Difference

12 percent of elected officials in local government have a disability, compared to 6.9 percent at the state level and 6.3 percent at the federal level.

Disability Type

Hearing impairment is the most common disability among elected officials.

Demographic Divide

The vast majority of politicians with disabilities are white, non-Hispanic men.

People with disabilities comprise an increasingly powerful voting bloc. An estimated 14.3 million people with disabilities voted in the 2018 midterms, surpassing the number of Hispanic/Latino voters (11.7 million) and nearly matching the number of African American voters (15.2 million). Twenty percent of all voters either had a disability

or lived with a person with a disability at the time of the last election.¹

In 2016, it was estimated that 62.7 million voters, had a disability themselves, or had a relative with a disability. Yet, despite the immensity of these numbers, people with disabilities are vastly underrepresented at all levels in elected office. In 2018, only 11 candidates with a disability were running for either the U.S. House of Representatives or U.S. Senate. Of these, five had either dropped out or lost in a primary. This is a mere 2.3 percent of the 470 congressional seats that were open.²

During the 2013-2017 Period

In an average year, from 2013-2017, there were an estimated 36,779 individuals who held elected positions as part of their primary job. Among those individuals, 10.3% had disabilities.

- This was less than the nearly one-sixth (15.7%) of all adults in the population who had disabilities.
- The most common disabilities among elected officials were hearing impairments (5.4%) and mobility impairments causing difficulty in walking or climbing stairs (4.7%).
- The rate of disability was slightly lower among elected female officials (8.3%) than among male elected officials (11.4%), and was higher among military veteran elected officials (18.4%) than among non-veteran elected officials (9.0%).
- The likelihood of disability was higher among native American elected officials. But it was not otherwise different significantly by race and ethnicity.
- Older people were more likely to have disabilities and be elected officials. Over one-sixth of elected officials age 65 or older had disabilities, compared to only 5% of elected officials under the age of 35 years.
- The percent of elected officials with disabilities grew from 8.5% in the 2008-2012 period compared to 10.3% in the 2013-2017.³

2020 Disability and Voting Accessibility Survey

- Voting difficulties among people with disabilities declined markedly from 2012 to 2020.
- About one in nine voters with disabilities encountered difficulties voting in 2020. This is double the rate of people without disabilities.
- Voting difficulties were most common among people with vision and cognitive impairments.
- Almost three-fourths (74%) of people with disabilities voted with a mail ballot or early in-person in 2020. This represents a significant increase from 2012 and is higher than the two-thirds of non-disabled voters who did so in 2020.⁴

U.S. Presidents with Disabilities



For most of these men, speaking publicly about their disability was discouraged during their lifetime.

William Jefferson Clinton, 1946- (hearing impairment; still wears hearing aids)
42nd President of the United States (1992-2000)

Dwight D. Eisenhower, 1890-1969 (learning disability)
34th President of the United States (1953-1960)

Thomas Jefferson, 1743-1826 (learning disability)
3rd President of the United States (1801-1809)

John F. Kennedy, 1917-1963 (learning disability, chronic back pain)
35th President of the United States (1960-1963)

Abraham Lincoln, 1809-1865 (major depression)
16th President (1860-1863)

James Madison, 1751-1836 (epilepsy)
4th President (1809-1817);

Ronald Reagan, 1911-2004 (hearing impairment)
40th President (1980-1988)

Franklin Delano Roosevelt, 1882-1945 (polio)
32nd President (1933-1945)

Theodore Roosevelt, 1858-1919 (blindness in one eye)
26th President (1901-1909)

George Washington, 1732-1799 (learning disability)
1st President (1789-1797)

Woodrow Wilson, 1856-1924 (learning disability, dyslexia, partially paralyzed)
28th President (1913-1921)⁶



Politics and Ideology

Using a scale composed of 10 political values, fully four-in-ten Americans with disabilities expressed a mix of conservative and liberal political values. Of those, 31% took more liberal than conservative positions across these questions and 26% were more conservative than liberal in their values. That closely matches those without disabilities, being slightly more likely to hold consistently liberal positions.⁵

Those self-identifying as having a disability were somewhat more likely than the general public to report being particularly engaged with the 2022 election. In a survey conducted in June 2022, fully 71% of Americans with disabilities said it “really matters who wins the election,” compared with 59% of Americans who do not have a disability.

Similarly, 41% of those who are disabled were following

the campaign “very closely” in June. By comparison, 33% of Americans without disabilities said the same.

“These differences are driven primarily by the fact that the disabled, as a group, are disproportionately older than the population. (sic) Though not all Americans with disabilities are older Americans, many of those 65 and older report being in some way disabled. And older Americans generally tend to be more attentive to politics and government than their younger counterparts. In other words, it is likely age and not disability status that drives their level of political engagement.”⁵

Why Voting Matters for People with Disabilities

“The lack of accessibility at polling places and in the ways people vote has not stopped people with disabilities from being politically active. They have been fiercely political throughout U.S. history—from the Depression-era *League of the Physically Handicapped*, which fought for the right to work, to the Capitol Crawl, and from the 504 sit-ins to the die-ins to save the Affordable Care Act, people with disabilities have long used their voices and bodies to make political change.... *Voting is one more way that people with disabilities can use their experiences to help influence the policy decisions made within their communities and their country—and their experiences are sorely needed.*”(emphasis added)⁷

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Rick Rader, MD, FAAIDD, FAADM, DHL (hon) is Director, Habilitation Center, Orange Grove Center; President, American Association on Health and Disability; Board, American Academy of Developmental Medicine and Dentistry; National Medical Advisor, National Alliance for Direct Support Professionals; Board, National Task Group on Intellectual Disabilities and Dementia Practices.

Allen Wong, DDS, EdD, DABSCD is a professor and the director of the Dugoni School of Dentistry AEGD and Hospital Dentistry program in the San Francisco area, and is the Global Clinical Advisor to the Special Olympics Special Smiles. He is past president of the AADMD and Publisher of Helen: The Journal of Human Exceptionality.

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The **O.S.C.A.R. Project:**

Fighting Labels, Opening Doors

By Arina Vinereanu, DDS, PhD

All children are special, yet, some are even more so. Children who do not fit into the usual patterns—for whom sitting, talking, walking, feeding or whatever other ordinary aspects of everyday life one could think of (or not) may be huge challenges—are one of the most underserved groups of population when it comes to dental treatment.

“Cannot be treated under common dental office circumstances” is a label, a verdict that often

families and cause them to push oral health to a remote level of concern, at least for as long as there’s no oral pain. But pain does occur eventually, and it only makes things worse, as any child in pain is less likely to cooperate with the dental team, especially when the latter is all made of unfamiliar faces.

Of course, this problem is not new, and there is obviously no easy way to solve it; yet some small steps can be made. The OSCAR Project

(where the acronym stands for Oral Special Care Academic Resources) is meant to be such a step. Initiated by the Romanian National Association of Paediatric Dentistry, OSCAR brings together Carol Davila

Daily challenges generated by a child with special health care needs may overwhelm families and cause them to push oral health to a remote level of concern, at least for as long as there’s no oral pain.

does not even imply that someone has actually tried and failed, and there’s more than one reason for this situation. Under- and postgraduate dental curricula are heterogenous when it comes to special oral care, and dentists able and willing to accept the challenge of a non-standard patient aren’t numerous. Health care systems vary a lot from one country to another, resources differ, as do society’s priorities and, in many regions of the world, sedation or general anaesthesia is not something one can easily get or afford. Daily challenges generated by a child with special health care needs (SHCN) may overwhelm

University Bucharest (Romania), Hôpitaux Universitaires de Strasbourg (France), Bambino Gesù Children’s Hospital Rome (Italy), Marmara University Istanbul (Turkey), and Special Olympics Romania in the project team, in the attempt to shake barriers and build bridges between dental professionals and families of children with special health care needs by encouraging cooperation of these two categories that have the child’s best interest at heart.

OSCAR is an Erasmus+ educational project. On one hand, it aims to bring useful practical information closer to those dentists who would



like to provide oral care to kids with general pathologies, but feel reluctant due to a self-perceived insufficient knowledge in the field of special oral care.

The Dental Professionals' section on the project's platform (open access <https://oscarpd.eu/>) reunites the experience of an enthusiastic group of professionals from the already mentioned 4 European countries; a growing number of general conditions are presented, with focus on oral implications whilst case reports with photos and videos come to make things easier to perceive. Concepts such as the Dental Home and Bedside Dentistry are explained and promoted. Paediatric Dentistry under- and postgraduate training programs are very welcome, not only to use this section in their teaching process, but also to contribute with own experience and suggestions.

OSCAR also addresses Parents. A dedicated section of the project platform provides practical information on efficient home oral care in 5 languages (English, French, Italian, Romanian, Turkish). The free downloadable brochure, along with the featured videos (including tutorials meant to increase the efficiency of the so-called "tele-dentistry") hope to give some useful clues on how to preserve the oral health of these special children for whom oral disease must not to be an extra burden.

There's one more thing that needs to be mentioned: virtual "covers" for the various chapters of the platform were done by children with or without special needs, all happy and eager to be involved. OSCAR warmly thanks all the children and parents who put their time, energy, dedication and willingness to help into active, priceless contributions to this project and strongly believes that parents and dentists can make an unbeatable team to grant all children happy, healthy smiles.

Dr. Arina Vinereanu DDS, PhD, is General Secretary of the Romanian National Association of Paediatric Dentistry and Former Councilor of the European Academy of Paediatric Dentistry.

MAKE SURE THEY'RE IN THE RIGHT CAR SEAT



[NHTSA.gov/TheRightSeat](https://www.nhtsa.gov/TheRightSeat)





Sylvia Lowe (circa 1932)

On the Value of Sleeping on the Floor in the Living Room

By Rick Rader, MD. FAAIDD, FAADM

Regular readers of *HELEN: The Journal of Human Exceptionality* are probably familiar with the most notable and renowned leaders and champions of the decades' old disability rights movement. But like all movements, there are the boots on the ground that have demonstrated their commitment and dedication without asking or receiving any notoriety. They are truly the unsung heroes who have paved the way by practice and example.

This is the story of Sylvia Lowe told by her son, Vern Lowe. Ms. Lowe provided respite care before the idea was ever promoted. She used her intuitive sense of empathy, compassion and sacrifice to open both her home and her heart to the disability community. Her son, Vern, recounts how he was (at times) made to feel like a second-class citizen, and eventually understood the purpose, value and honor of sleeping on a "camp bed" in the living room.

Ms. Lowe's work contributed to the mission of Mencap, one of England's earliest and most respected disability programs. Its history is reminiscent of many of the earliest parent-driven groups in America.

In 1946, Judy Fryd, a mother of a child with intellectu-

al disabilities (known as "learning disabilities") formed "The National Association of Parents of Backward Children." She wrote to "Nursery World" magazine inviting other parents to contact her. Many wrote back to Judy expressing their anger and sorrow at the lack of services for their children.

In 1955, the association changed its name to "The National Society for Mentally-Handicapped Children" and opened its first project, the Orchard Dene short-stay residential home. In 1958, the National Society launched a ground-breaking project called the Brooklands Experiment. This compared the progress of children with a learning disability who lived in a hospital with a group of children who were moved to a small family environment and cared for using educational activities modeled on those in "ordinary" nurseries.

After two years, the children in the home-like environment showed marked improvements in social, emotional and verbal skills. The success of the experiment was published around the world. Since that time, Mencap has made a significant contribution to the progressive and humanistic models practiced in the United Kingdom and around the world.

Lessons Learned From the Visionary Eyes of My Mother

By Vern Lowe

This is a true story I thought my shame would prevent repetition. Fortunately, a chance meeting with Rick Rader changed events, he suggested placing on record my experiences as a tribute to my mother's memory and endeavors for people with Down syndrome.

A proud American immigrant, I was born shortly after the end of WW2, 1945, in Coventry, England. With modest and humble origins,

and completely free weekend breaks to care for the individuals in our home. At that time, life expectancy of people with Down syndrome was relatively short, and my mother's caring offer was well received.

We lived in a small, three-bedroomed house in the UK. When our visitors arrived, I was relocated to a "camp" bed in the living room of our home. At first, this was quite an adventure and I'm sure I enjoyed it,

as a young boy. My protests fell on deaf ears, and on occasion, resulted in loss of privileges.

I also recall my mother organizing a "Sports Day" in the gardens of a local pub and persuading the then-Captain of the British Lions, Commonwealth Rugby Team (Phil Judd) as Guest of Honor, to publicize the Down Syndrome Society's support efforts and increase the normal life events.

I would hope recording Mother's efforts to develop the more sensi-



my mother was a particularly caring, sensitive, and personable lady who became involved in the local offices of the Down Syndrome and Mentally Handicapped Society. In the late 1940s, this was a relatively new and certainly underfunded institution in Great Britain and had very limited resources. My mother rapidly developed a circle of friends and relationships with both the parents and children of the Society.

An underlying feature of the society was the loving and appreciative mentality of the patients of all ages. In those early days, parents and carriers had very limited personal time, and my mother determined to offer informal,

but as the months and years rolled on, it became a source of dissatisfaction to me, as a young, insensitive, and uncaring boy. On occasions, our guest had "accidents" during the night, and despite their warm and demonstrative manner, I was unimpressed with having to vacate my bed, regularly on a Friday or Saturday night.

For 10 years after WW2, Great Britain experienced rationing of food and certain non-essential goods like chocolate, candy and cookies. Sharing these delights with my enlarged family had a further detrimental effect on my greedy and insensitive behavior

tive and caring aspects of my life have proved positive, if only by placing on record her contribution to improving the lives of others.

Vernon "Vern" Lowe is the CEO and President of Felters, an internationally-known leader in the development and manufacturing of felt and specialist nonwoven materials. They were established in 1890 and are located in Roebuck, South Carolina. Vern is a professional engineer by training.

BUILDING a **VILLAGE** OF **SUPPORT & CARE** FOR INDIVIDUALS WITH **AUTISM**

By Shelly L. Huhtanen



The author's son, Broden, working in The Unumb Center print shop, part of their Voc Rehab training. Photo provided by Shelly L. Huhtanen

In 2008, my son, Broden, was diagnosed with severe autism when he was around 26 months old. Over the years, I eventually learned to focus my energy on what I can do for my son now and to plan for his future. There was a time, when he was first diagnosed, that necessarily was not the case. There were times when I would spend too much energy trying to figure out what I did wrong or what I missed because I blamed myself for his diagnosis. There was a lot of wasted time spent on trying to see if there was a way that I could “pull him out of autism” by finding the magic pill, only to be disappointed and pulled into a deeper depression because in my mind, I had failed my son.

As my husband and I experienced each year of Broden's life, I realized that I couldn't freeze time. I had to see him for who he is and love him because he became the child I only knew him to be. If he didn't have autism, he would be someone different. Instead of asking myself the question, “How do I change my son?” I started to ask myself questions such as, “What can I do to support him now?” or “How can I build a village that

celebrates Broden for who he is, and with the right supports, he could continue to grow and learn?”

With the right team and positive collaboration, I learned that ABA, Applied Behavior Analysis, was a therapy that was working for my son. I have been in a conundrum for years because my husband serves in the military, and access to care has been a consistent issue since Broden was diagnosed 14 years ago. My husband and I have worked together to plan ahead, attempting to maneuver within the constraints the military has given us over the years. My husband has extended at installations so our son could continue care and when we were at a point that we had to move, I would research and ask other military families that have children who receive care from ABA clinics, to find the best fit for our son. We have spent years fighting through pointless TRI-CARE bureaucracy so our son's access to this life-saving care would not be interrupted. At times, I have asked myself, “Where does it end?” Our family has been fortunate to land at an installation where there is a place for our son, a place where he will not outgrow his village of support.

Years ago, a friend and fellow advocate invited me to



Instead of asking myself the question, “How do I change my son?” I started to ask myself questions such as, “What can I do to support him now?” or “How can I build a village that celebrates Broden for who he is, and with the right supports, he could continue to grow and learn?”

attend the Autism Law Summit at Georgetown University. This was the first time I witnessed Lorri Unumb speak; she was the founder of the summit. Years before Broden was diagnosed, Lorri’s son, Ryan, was diagnosed with autism. Lorri saw great improvement in Ryan with ABA therapy, but soon realized that the state of South Carolina, nor any other state, did not provide a law that ensured children with autism had access to autism insurance. After Lorri drafted a bill on her kitchen counter, “Ryan’s Law” was passed in 2007 and started a grass roots movement. Parents from all over the country were contacting Lorri and her husband, Dan, “I heard you had the first bill passed towards autism insurance reform. How did you do it?” This collaborative group of parents and advocates grew over the years and later became the Autism Law Summit. Now this group meets every year and has grown to over 300 members.

In the auditorium that day at

Georgetown University listening to Lorri, I sensed a shift inside me in the way I saw not only my journey in support of Broden, but Broden’s journey of growth as well. Lorri said, “Our children are getting older. What are we going to do to support them? We need a plan. They deserve to have productive lives just like everyone else.” After hearing the story about her drafting up the first piece of autism in-



Lorri and Dan Unumb holding the plans for the new campus to include services for adults with autism. Photo provided by Shelly L. Huhtanen

insurance reform, I knew she was a person of action, and I was hooked. She energized me and I was reminded that my son has value as a person and as a member of society. Broden deserves

appropriate care and a purposeful life, just like everyone else.

Years later, our paths would cross once again when Mark and I found out that we would be stationed in South Carolina. I remember being in the car at Fort Benning, Georgia, googling ABA clinics when Mark told me that he was officially notified that we would be moving farther east. I saw an ABA clinic, the Autism Academy of South Carolina, that looked promising. As I read their mission statement and services they provided, I realized that this place could be a good fit for Broden. I clicked on the link to see who had founded the clinic. The founder was none other than Lorri Unumb, the same person I listened to at the Autism Law Summit years ago. “Mark, this is it,” I told my husband. “This is the place for Broden.”

Broden has now been a client at this ABA clinic for over three years. His team has gelled and his BCBA (Board Certified Behavior Analyst), Jaime White, has become more than just his Program Manager, she has become a part of our family. Jaime understands that Broden’s life and his family’s lives do not start 8:30 am and end at 3:30 pm. Monday through Friday. She cares enough to be there through not only the times we celebrate the progress Broden has

made; she is there through challenging times too. She has continuously kept our quality of life in mind when she is building Broden's programs and for that, I am grateful. The Executive Director, Anslie Patrick, and her team have continued to push and work tirelessly to build a team to provide the best care possible for their clients. Anslie is always creating ways to better serve the clinic's clients and listening to parents to find ways to not only provide support to their clients, but also ways to support their clients' families.

In 2018, the Board of Directors voted to rename the clinic, The Unumb Center for Neurodevelopment while also expanding the services they provide. After acknowledging the gaps in services existing in the area, they decided to work on a solution themselves to support Columbia and its surrounding communities. The Unumb Center, a nonprofit organization, is now utilizing a partnership with Voc-Rehab for pre-employment training, created a psychology department to provide diagnostic services, as well as building a social skills program. Individuals with autism have access to pre-employment and social skills even if they do not receive ABA services from the clinic.

Acknowledging that there is still work to be done, The Unumb Center is currently in the planning process to build a campus that will provide an adult life center to include opportunities for residential living. There will also be opportunities at the campus for employment training and a plan for their clients to put their training to use by providing employment opportunities not only on the campus, but also in the local community. Since the ABA clinic's opening in 2010, they have not only strived for best practices to ensure their clients receive quality care, but they are also continuously identifying gaps in services and growing to meet client's and their family's needs. This not only benefits Broden and Lorri's son, Ryan, it benefits our entire autism community.



The entrance to The Unumb Center for Neurodevelopment in Columbia, South Carolina



Individuals with autism have access to pre-employment and social skills, even if they do not receive ABA services from the clinic.

Currently, I've been given the opportunity to serve on the Board of Directors where I can be part of the team that is working to build a better and more prosperous future for individuals like my son. Being part of a team that focuses on solutions and who builds relationships in the local community to provide support to our village is empowering and uplifting. I no longer ask myself, "Why me? Why Broden?" Now I tell myself, "I celebrate my son and

I can do this with love and support." I also remind myself that we can overcome anything with the right village.

Shelly Huhtanen teaches Public Speaking at the University of South Carolina for the Pathway Program. Her column, Puzzles and Camo, for EP magazine shares her experiences of raising a child with autism while serving in the military. She has also authored a book entitled, "Giving a Voice to Silent Many." As a military spouse, she has lobbied Congress for better access to care for military families raising children with autism, and is currently serving on the Board of Directors with The Unumb Center for Neurodevelopment.

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Steve Perlman, DDS, MScD, DHL (Hon.) has extensive experience through his private practice and his role as Clinical Professor, Boston University School of Dental Medicine; has an Academic Appointment at the University of Pennsylvania School of Dental Medicine; is Co-founder and Past President of the AADMD.

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