The Mayor’s Office for People with Disabilities (MOPD) is proud to announce that its innovative employment program, NYC: ATWORK, has received the Zero Project Award for 2021. The Zero Project focuses on the rights of people with disabilities globally. The award honors the innovative and effective policies and practices that improve the lives of people with disabilities around the world.

The Zero Project was initiated by the Essl Foundation in 2008, with its mission on supporting the implementation of the Convention on the Rights of Persons with Disabilities (CRPD) of the United Nations and to work for a world without barriers. The approach of the Zero Project is to research and share Innovative Practice and Policies worldwide, by engaging with a worldwide cross-sectoral network of innovators, decision-makers and opinion leaders.

More than 5,000 experts, with and without disabilities, in more than 150 countries, have been actively contributing to the Zero Project in the past years. In a four-year-cycle, each year the Zero Project focuses on four topics including Employment, Accessibility, Independent Living, Political Participation and Education.

“Every day, we work to create new solutions to help the millions of people with disabilities around the world. NYC: ATWORK is an example of how we are making progress,” said MOPD Commissioner Victor Calise.

“The International Day of Persons with Disabilities celebrates the global progress to increase access for the disability community in all facets of life,” said Mayor Bill de Blasio.

“NYC: ATWORK is a network of passionate people actively creating solutions and opportunities for jobseekers with disabilities.”

This public private partnership recruits, pre-screens and connects New Yorkers with disabilities to job opportunities and internships with their established business partners in a myriad of sectors.

“Originally a three-year grant-funded initiative, NYC: ATWORK has grown into a powerful network of jobseekers, businesses and service providers.”

The winners of Zero Project awards are announced every year on the United Nations International Day of Persons with Disabilities. This celebration aims to promote the rights and well-being of persons with disabilities in all spheres of society and development.

As one of the Zero Project awardees, the NYC: ATWORK team will be presenting the city’s employment initiative to disability stakeholders around the world.
Happy New Year everyone! Although it’s only a number on a calendar, I cannot help but feel a sense of triumph and changing winds as we look forward to 2021.

In the past year, we were faced with the ongoing global pandemic. All the while, we found ways to connect with one another under extraordinary circumstances and continue the progress to make New York City more accessible for all.

This month, it is my honor to announce the release of the 2020 edition of AccessibleNYC - MOPD’s annual report. This year’s report is unique in that it discusses in detail the challenges we faced during the pandemic response and the path forward to make the City even more inclusive during the recovery process. You can read the full report online at NYC.gov/AccessibleNYC.

As the City’s pandemic response continues, MOPD remains in constant communication with the disability community. We hold a monthly call with the disability community, if you would like to attend the Jan. 8 call, you can join in using the phone number below.

Friday, January 8th 1:00pm
Phone: +1 646-876-9923
Webinar ID: 885 3449 2671

As we enter the last year of the de Blasio Administration, we celebrate the progress that we have made for people with disabilities but are not slowing in our efforts to provide access and inclusion for all New Yorkers and visitors with disabilities.

Please continue to stay safe, wear your face coverings (if you are medically able to), and maintain your social distance. With a vaccine recently approved, these next few months will be a critical time for all of us as we fight back the spread of COVID-19 once and for all.

Ciao,
Commissioner Victor Calise
DOT Restricts Animals On Planes

T he U.S. Department of Transportation (DOT) recently announced that it has revised its Air Carrier Access Act (ACAA) regulation on the transportation of service animals, which they claim is meant to ensure accommodations for people with disabilities as well as the safety of all passengers and airline staff.

Only certified service dogs are to be considered service animals. Therefore, airline carriers should now consider emotional support animals as pets that would travel in the cargo area of airplanes instead of in the cabin alongside passengers. This move from the DOT comes after several years of complaints about the proliferation of pets of various species traveling in the cabin of airplanes with their owners who claimed they were necessary emotional support animals.

Since most of these animals are not professionally trained, there have been many instances where they caused disruption or harm to genuine support dogs or other passengers. Furthermore, the DOT states that too many passengers were fraudulently representing their pets as service animals. They allege that some of these animals are not actually for support, but rather just pets that their owners would like to have in the cabin for convenience and/or to avoid the cargo area boarding fee.

“People abused it, and it got out of hand,” said Marilyn Tucci, advocacy and outreach coordinator of Suffolk Independent Living Organization (SILO). “People have tried to bring a peacock, a snake and other animals. Why would they do that?”

However, some disability advocates claim that the new rules are too rigid, including National Disability Rights Network Exec. Dir. Curt Decke r. “There’s a large number of people with intellectual and emotional disabilities that benefit from having that kind of support on a trip,” said Decker in a New York Times article.

The DOT defines a service animal as a dog of any breed that is individually trained to perform tasks for the benefit of a qualified individual with a disability, including a physical, sensory, psychiatric, intellectual or other mental disability.

It also allows airlines to require the passengers to fill out a DOT form attesting to the service animal’s health, behavior and training. The form also asks for an attestation when taking a long flight that the service animal can either refrain from relieving itself or can do so in a sanitary manner. Carriers are also allowed to require that service animals are harnessed or leashed.

The final rule prohibits airlines from requiring passengers with a service animal to physically check-in at the air-port instead of using the online check-in process.

Airlines can require that a service animal fit within its handler’s foot space on the aircraft and gives them the right to refuse to transport service animals that exhibit aggressive behavior.

“Most of the blind community is very happy about this, because it’s going to be better for people with legitimate service animals. We ask to be seated by the bulkhead, which has the most room for our dogs,” said Tucci. “When an animal isn’t well-behaved, it can become a big problem. I am blind, and my dog is a guide dog, which performs specific tasks. My dog is my eyes. People who are blind have been asking for this for years.”

Boro Pres Names Disability Activist to Advisory Post

Donovan Richards, who recently won the Queens Borough President race, has put together his transition team, a group of more than 100 leaders — to help him form new policies. Previously he was a member of the City Council.

Among those chosen is Mike Schweinsburg, president of the 504 Democratic Club, who will serve as disability advisor. A longtime disability activist, he organized the first Disability Pride Parade in New York City and is Disability Liaison from Assembly Member Harvey Epstein’s office.

“At long last, the disability community has a seat at the table,” Schweinsburg said. “There is a strong indication that Borough Pres. Richards will for first time give the disabled community more than a glance.

“We are the largest minority and the second largest voting bloc,” Schweinsburg said.

Richards has chosen three co-chairs to lead his transition team — Jackson Heights Assembly Member Catalina Cruz; former Manhattan Borough Pres. Ruth Messinger and Queens Public Library President and CEO Dennis Walcott, who previously served as NYC Schools chancellor and deputy mayor.

Rhonda Bindawill serves as the executive director overseeing the transition.

Astoria Council Member Costa Constantinides, who ran against Richards, will serve as chair of the planning committee that oversees land use and development.

Southeast Queens council member I. Daneek Miller will serve as co-chair of the transportation committee alongside Juan Restrepo.

Newly elected Assembly Member Khaleel Anderson was named to Richards’ youth committee and his personnel committee.

The Personnel/Appointments Committee will be co-chaired by Franck Joseph, the deputy commissioner of the New York City Commission on Human Rights and Ibrahim Khan, the chief of staff to the New York Attorney General.

The Youth Committee will be chaired by political strategist Martha Ayon, the head of Azul Public Solutions.

Other appointees include Jo-Ayn Yoo as chair of the Immigration Committee; Michael Mallon as chair of the Community Boards Committee; pastor and community leader Bishop Taylor as chair of Community Affairs; Juana Ponce de Leon as chair of the Communications Committee and Bertha Lewis as co-chair of the External Affairs Committee.

Richards has also named VP for Communications and Marketing at Queens College Jay Hershenson as the Education Committee chair; Executive Director at Community Voices Heard Afua Atta-Mensah as chair of the Policy Committee; Executive Director of Chhaya Annetta Seecharan as chair of the Economic Development Committee; Executive Director at the Jamaica Center for Arts and Learning Cathy Hung as chair of the Tourism, Arts, Parks, Entertainment and Sports (TAPES) Committee and Major Sharon Sweeting-Lindsey, of VETS, Inc, as chair of the Veterans and Veterans Affairs Committee.
Advocates for Children File Lawsuit Against DOE

Some parents have received a notice in connection with a lawsuit that is now in federal court, J.L., et al. v. New York City Department of Education (Case No. 17-cv-7150 S.D.N.Y.).

This is an ongoing lawsuit where Advocates for Children and Greenberg Traurig represent the plaintiffs.

The letter was sent in connection with a lawsuit that Advocates for Children filed for three parents because their children did not receive proper in-school nursing, porter and/or transportation services and accommodations.

Anyone who has requested any of these services or accommodations for their child might receive a letter. Disclosing these documents will not change in any way the rights that the child has in receiving services from the DOE, and the DOE cannot use the parents’ decision here in any way to impact the child’s rights.

Parents do not have to produce any documents that they may have related to the case. This only relates to the student’s records kept by the DOE.

If parents opt out, their child’s personal information will not be produced. Although the child’s records may be produced, any personal information will be removed from the documents so the information is not seen by the plaintiffs’ attorneys.

Burke Unveils Outpatient Physician Practice

Burke Rehabilitation Hospital and Montefiore Department of Rehabilitation Medicine have launched a new outpatient physician practice, a comprehensive health resource for the community.

Housed in a classic building with artwork that provides therapeutic benefits, the multidisciplinary practice synthesizes the latest treatment technologies in a healing environment, to optimize the patient experience.

There are 11 practice rooms, with onsite capability for procedures such as epidurals and joint injections, ultrasound and EMG diagnosis and advanced medical and therapeutic treatments. The physicians specialize in a wide variety of conditions, including stroke, spinal cord injury, brain injury/concussion, cardiac disease, pulmonary disease, orthopedic surgery, amputations, musculoskeletal disorders, chronic pain, dementia and arthritis. Collaborating in multidisciplinary teams, the practice oversees individualized care plans to help patients maximize their recovery and achieve wellness goals.

New York Medicaid Changes in 2021

By Carrie Helgerson

Historic changes to New York’s Medicaid Program were recently implemented with the adoption of the State’s fiscal budget.

The most severe cutbacks take aim at long-term community home care Medicaid services including Personal Care Services, the Consumer Directed Personal Assistance Program (CDPAP), home health care services, private duty nursing, and the Assisted Living Program. The new rules impose a 2.5-year “look back” period or period of eligibility due to a transfer of assets.

This differs from the previous rule, which did not require a lookback period for community-based care. The changes initially intended to take effect Oct. 1, 2020, have since been delayed until April 1, 2021, as a result of the Public Health Emergency stemming from the spread of the coronavirus. Therefore, beginning April 1, 2021, any resident filing a new application for community-based Medicaid benefits will be subject to the new rules.

Effective April 1, 2021, New York residents filing a new application for Community Medicaid services will be required to provide 30 months of financial records for themselves and their spouses prior to the date that Medicaid coverage is sought to begin. The 2.5-year look back period will apply to outright transfers as well as transfers to a trust. The local Department of Social Services or Medicaid agency will perform a forensic accounting of these records, looking for any transfers of assets or gifts made during the lookback for less than fair market value.

The look back period will retroact to Oct. 1, 2020, the effective date of the rule while the 30-month period is being phased in. A penalty period will be imposed for any non-exempt transfers of assets, during which time, the applicant will be considered ineligible for Medicaid long-term community home care coverage.

The period of ineligibility would begin the first day the approved applicant is due to receive home care services. According to the Department of Health, transfers made prior to the Oct. 1 retroactive date are exempt from scrutiny.

Persons submitting new applications for Community Medicaid services prior to April 1, 2021, will not be subjected to penalties for transfers of assets under the Medicaid home care system. It has also been decided that those individuals already receiving long-term community Medicaid services, are grandfathered in, and will not be affected by the new rules.

Other changes that were set to begin Oct. 1, 2020, imposing heightened standards for eligibility for the Community Medicaid Program are currently underway.

Carrie Helgerson is a staff member at Brandau Law.
Legislators & Advocates Want Subway Access

The Metropolitan Transit Authority (MTA) has been left in severe financial straits during the COVID-19 economic crisis, but that won’t stop advocates for transit riders with disabilities from advocating for key accessibility commitments that so far remain unmade.

Assemblymember Jeffrey Dinowitz, State Sen. Andrew Gounardes, Center for Independence of the Disabled – New York (CIDNY), Brooklyn Center for Independence of the Disabled (BCID), Bronx Independent Living Services (BILS), Disability Rights Advocates (DRA), NYPIRG Straphangers Campaign, and Riders Alliance all gathered virtually to discuss key accessibility elements of the Fast Forward plan proposed by former New York City Transit (NYCT) Pres. Andy Byford as well as other sought-after improvements.

“Funding capital improvements to bring our subway system into compliance with federal disability requirements is something the federal government should have been doing regardless of pandemic, but right now it is even more critical that Congress include the full funding request by MTA Chairman Foxx and Gov. Cuomo, said Dinowitz.”

Legislation Developed

In 2019, Gounardes and Dinowitz announced legislation that was developed with feedback from many of these organizations about what steps need to be taken to bring full accessibility to New York’s subway system. One of these recommendations, the establishment selection criteria for how to equitably prioritize subway stations for accessibility upgrades, was signed into law earlier this month.

More Recommendations

Additional recommendations on how to bring the subway system into full accessibility include Codifying – the Fast Forward timeline of making at least 50 additional subway stations accessible in the 2020-24 capital program; 130 new accessible stations in the 2025-29 capital program; and all remaining stations in the 2030-34 capital program.

Accessibility Requirement

Also recommended was a requirement that any station closure or substantial renovation six months or longer must include full accessibility as a key element; providing real-time, up-to-date and accurate information regarding elevator outages and alternate routing and make this data available via third-party Application Programming Interface (API).

In addition, revising maintenance practices to improve reliability of elevators and wheelchair lifts in order to provide continuous and uninterrupted elevator service, and design and site elevators to provide similar stair and chair-free access/egress times was recommended.

Long Overdue

“Ensuring ADA compliance throughout New York City’s transit system is a necessity, not a luxury. We must make sure that all residents, including people with disabilities, are not cut off from essential services. Quite frankly, ADA compliance is long overdue and the pandemic has only shown how far the MTA is from true accessibility for all,” CIDNY’s Exec. Dir. Susan Dooha.

Now in 2020, the legislators and advocates are part of a chorus of calls for federal funding to simply maintain mass transit service and prevent cuts during the COVID-19 pandemic, let alone fund future capital improvements for elements like accessibility.

Desperate Calls

“We desperately need federal funding to help the MTA give us what we have deserved for so long: full and equal access to the subways,” said Jessica De La Rosa, systems advocate at BCID. “If Washington doesn’t come through, or we don’t get funding from state sources, people with disabilities will continue to face an inaccessible, discriminatory system.”

Congestion Pricing

One major revenue stream that was intended to help pay for future capital projects such as subway elevators was the start of congestion pricing in January 2021, but delays from the current United States Department of Transportation (USDOT) have potentially delayed that start until 2023.

The USDOT has also been increasingly criticized for an outdated funding formula that mandates 80 percent of federal transportation funds go toward highways. Transit experts and advocates have suggested that an even split of that funding would make a significant difference in transit agencies’ ability to modernize subway systems.

“We are counting on Albany to come through if Washington doesn’t,” added Joe Rappaport, executive director of BCID.
Through the Democratic presidential debates, and then again during the election, the term “Medicare for All” was bandied about. Unique among Democratic candidates, President-Elect Biden opposed “Medicare for All”, but supported a “public option” as part of a plan to enhance Obamacare.

“Medicare for All” was attacked by Republicans and conservative columnists, as creeping socialism. Nevertheless, only a few years ago, Tea Party supporters, in an expression of incredibly confused populism, carried signs that said, “Keep the government’s hands off my Medicare,” as if Medicare was private insurance, and not a government program. Republican politicians wanted to protect Medicare for seniors, and still say they do (while they propose cuts, etc.), but consider “Medicare for All” a socialist idea.

Long before his presidential candidacy and even before he ran for governor of California, Ronald Reagan opposed Medicare for seniors. In 1961, he predicted that if passed, Medicare (just for senior citizens) would begin the country’s descent “into socialist hell.” Pres. Lyndon Johnson signed Medicare into law in 1965. At that time, only 54 percent of those over 65 had insurance that covered hospitalization, and private insurance routinely dropped older customers as too risky. Three years later, 96 percent of seniors had coverage for hospitalization.

By 1987, Pres. Ronald Reagan was proposing an expansion of Medicare to cover catastrophic illness for seniors. He said it would give older Americans “…that last full measure of security…” and would limit out-of-pocket expenses to a predictable, affordable amount, no matter how much healthcare seniors consumed.

What was originally seen by Pres. Reagan as a descent into “socialist hell” was seen by the same man in 1987 as “security.” It became OK for right-wingers to protect Medicare for seniors. Perhaps because of Medicare, seniors were living longer, retiring, using Social Security retirement benefits to fund retirement and using Medicare to stay healthy and independent.

The cowardice of some politicians accounts for the hypocrisy of supporting and expanding Medicare for seniors, while denying the same coverage to the rest of America. Seniors vote as a bloc and are more likely to vote than younger Americans. Seniors as a group support Medicare and are unafraid of creeping socialism when they do. However, many—even seniors—oppose “Medicare for All” as a socialist proposal.

Now that the heat of the presidential election is almost over (as I write this, Pres. Trump has yet to concede) the Biden Administration will address healthcare reform. There were problems with Obamacare for people with disabilities, but preexisting condition exclusions and waiting periods have been eliminated by the Affordable Care Act (ACA) and so have annual and lifetime caps on care. The fact that the ACA allowed limits on durable medical equipment and medical supplies was the bad that came with the good, and we resolved to make it better. United Spinal intends to address this lingering Obamacare issue with the new administration, but we, of course, still support the ACA.

It is time, however, for those who oppose “Medicare for All” to explain why it’s OK for some, but not everyone else.

Continued on page 9
Sammi Haney, 9, has a significant role in the Netflix series “Raising Dion.” Haney, who lives with her family in San Antonio, Texas, is an up and coming actor with osteogenesis imperfect (OI). The condition, also known as brittle bone disease, causes a person’s bones to be very weak and can cause many other medical problems. This makes it very easy for an individual with OI to break or fracture their limbs and they may have many injuries by the time they are as young as six years old. According to Haney’s Dad she has broken hundreds of bones in her lifetime just by doing simple things, such as moving around in her sleep or even sneezing too hard. She wants to do all she can to be a good example and advocate for people with disabilities.

Haney is spreading awareness by sharing her story and selling shirts and other apparel through her company “Sammi Haney’s Disability Shirts”. She has many different designs that include phrases like “See people, not labels”, “Different does not equal less” and “The only disability in this life is a bad attitude”. Her parents run an Instagram account for her where she posts updates and videos of her surgeries and physical therapy. She also raises awareness by supporting charities such as Morgan’s Wonderland, Tiny Super Heroes, Make-A-Wish and more.

The young actor was cast in the role of Esperanza in Netflix’s “Raising Dion”. When she heard about the role, she got the script and sent in an audition video. According to Haney’s Dad, she hadn’t done much acting before, but she watched a lot of shows and movies on her iPad and wondered what it would be like to be in one. Her parents told her to be herself and have fun with it. She later heard back that she was the only audition that made everyone in the room laugh. “Raising Dion” is about a young boy who discovers he has superpowers, such as moving things with his mind, teleporting and becoming invisible. The show follows his single mother who struggles to hide his powers from the public and keep them under control, while trying to figure out where they came from and manage her daily life tasks. She is afraid of anyone seeing him use his powers and doesn’t know how to prevent this from happening while he is in school.

Esperanza is Dion’s best friend in the show. She helps him create his superhero costume and come up with a cool name. She looks out for him and is always ready to stand up for him. She is portrayed as sassy, clever and patient. “Raising Dion” currently has one season streaming on Netflix, but has been renewed for a second season to start filming in January 2021. In addition to her role on “Raising Dion”, Haney recently announced on Instagram that she has been booked for her first Disney role. She hopes her part in “Raising Dion” will help remove the stigma surrounding people with disabilities on TV. “When my parents told people about me being on a Netflix Series, it was disappointing that some of them assumed it must be a show about my medical condition, as if that is all they could see about me, she said.”
Hello Able readers. We are the Center for Independence of the Disabled, NY. You may also know us as CIDNY. We’re happy to be sharing the first of our new monthly columns here in Able Newspaper with you. You might see a few different names writing this column, but our goal is the same; to share information that we think you will find interesting, insightful, and useful.

You can always let us know what you think by emailing us at able@cidny.org.

The past year has been a difficult and unprecedented time for us all. We made it through and we have high hopes for 2021.

First and foremost we saw the outbreak of COVID-19. As of this writing, we still haven’t gotten the pandemic under control, but there is good news. Health care professionals have learned more about the virus. We have learned more about safety and prevention. It’s become easier to get a test (find out how to get a test in NYC at http://nyc.gov/covidtest). We should also see some positive news once the vaccine becomes more widely available later this year.

2020 was also an election year with national and local implications. We hope and believe that 2021 will bring more inclusion for people with disabilities, better voting accessibility and a better understanding for legislators on how policies affect people with disabilities.

Every year we continue to make strides in access and equality and we expect the same in 2021. In 2020 we fought for equality in transportation, voting, health care, food access, housing and more.

We hope to see more ADA compliance in 2021.

We’re happy to say goodbye to 2020. Here’s to 2021!
DIY Service Dogs with Medical Mutts

When it comes to do-it-yourself projects, training one’s own service dog doesn’t typically show up on anyone’s to-do list. A service dog organization has launched an online program to help owners train their own dogs.

Training a service dog is a long and complicated process that until recently, was only done by specialized trainers. It usually takes more than two years to get a service dog from a reputable organization and the costs can go up to $25,000. Learning how to do it oneself makes sense, when most people are stuck at home.

“You can’t start training service dogs without a good deal of guidance, even if you’re an experienced pet dog trainer,” said Jennifer Cattet, executive director at Medical Mutts, an organization that specializes in medical detection dogs. “Service dog training is a specialty, with practical and legal requirements. If you don’t have experience in this industry, you will make mistakes.”

For years, Medical Mutts has offered private and group classes, teaching owners who could travel to their facility how to train their own service dogs. But 2020 has presented unprecedented challenges and in order to help those who might be confined at home the organization is expanding access to its expertise through online options.

For those with qualifying dogs, on a budget and have the time this is a cheaper way to go.

The program is divided into four different segments, with assessments at every level. The owners and their dogs don’t need any training experience to get started and can enroll at any age.

The classes are live and interactive. Owners learn how to get the best out of their dogs and train them to do more than 30 behaviors. As they progress through the program, the dogs learn to help with a specific disability. UC Regents sought a stay of the injunction, in the hope of retaining their discriminatory policy.

DIY Service Dogs with Medical Mutts

On October 9, DREDF, along with other disability rights organizations, filed an amicus brief in Smith v. Regents of the University of California defending a preliminary injunction requiring the University of California (UC) school system to stop using the SAT and ACT as part of their admission process.

The ruling recognized that, under UC’s so-called “test-optional” policy, SAT and ACT scores afforded privileged, non-disabled students a “plus factor” in admissions that students with disabilities could not achieve due to a lack of appropriate accommodations and accessible testing sites — a problem highlighted and exacerbated by the COVID-19 pandemic. UC Regents sought a stay of the injunction, in the hope of retaining their discriminatory policy. DREDF’s brief details why the case was rightly decided.

Advocates Get Landmark College Admissions Decision

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UNITED SPINAL NOW Continued from page 6

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“Medicare for All” provides a consistent approach to healthcare and to paying for it. And by the way, despite everyone’s fears that national healthcare is inferior to our system and those opposing national healthcare subjecting us to a constant refrain of “we have the best healthcare in the world,” compare our coronavirus numbers with democratic countries with national healthcare systems. We appear to be a developing nation, not the country providing the best healthcare in the world.

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Shedding Light on Rare Form of MD

Ian Rys, a resident of Port St. John, Fla., was diagnosed with facioscapulohumeral muscular dystrophy (FSHD), one of the most common forms of muscular dystrophy, when he was 17 years old. His doctor told him and his mother that he would likely die before he turned 40. Defying this prediction, Rys is now 54 and has dedicated himself to raising awareness of this rare disease to help others understand the need for treatment options.

FSHD is a rare, progressive and debilitating disease characterized by progressive skeletal muscle loss that initially causes weakness in muscles of the face, shoulders, arms and trunk. Eventually, the disease progresses and causes weakness throughout the lower body. Patients often experience significant physical limitations including the inability to smile and difficulty using their arms. Eventually many patients must use wheelchairs or other mobility devices. There are currently no approved therapies for this disease.

Rys’ journey has not been an easy one. After being given a grim diagnosis, he had to work through his emotions including anger, fear and disbelief. Despite his struggles, he has lived a full life. He is a musician who played in a band during his younger years. He was also able to work to support his wife and four children as his disease slowly progressed. But as his health and mobility declined after age 50, he decided that he needed to make more of an effort to meet others living with FSHD. He attended his first patient conference hosted by the FSHD Society in 2018. It was the first time he had ever met another person living with FSHD. That event changed his life.

In the four years since attending that conference, Rys has continued to reach out and tell his story to help others understand the need for treatment options.

Technology Available For People With Vision Loss

Technology has transformed so many aspects of our world and for people with visual impairment technological innovations can be the key to living even more productive and independent lives.

New and emerging technologies and developments in areas such as artificial intelligence, spatial orientation and virtual reality are changing the approach to solutions for vision loss.

The technology used in instruments that extend human vision into space is being utilized by vision technology developers in devices that help people with vision loss with everyday tasks here on earth. Augmenting senses has allowed scientists across many fields to continue to work without the use of sight. Devices designed to help people with low vision, stimulate the remaining functioning vision to improve the quality of life for users.

Software driven smart glasses, navigation systems, and smart phone apps are other examples of technologies that can expand the world for people who are visually impaired. People may have a hand magnifier that they use for reading, but they may not know about screen readers for their computer or accessibility features for their phone.

Each person’s situation is unique, and it is important that people who have visual impairment ask their own doctors about which technologies are most suitable for them. The good news is there are a lot of innovative devices available to help people with mild, moderate, severe vision loss or blindness. Organizations such as Lighthouse Guild are now the connecting rod between evolving technology and the people that can benefit from it.

There are also podcasts and other resources for people who would like to learn more about technology that is changing the world for people with vision loss. For example, Lighthouse Guild’s podcast, “On Tech & Vision with Dr. Cal Roberts,” explores big ideas about how technology is helping people with vision loss. “Blind Abilities” produces podcasts dealing with accessibility, technologies and devices for people who are blind, visually impaired and deafblind.

The Blind Tech Guys podcast discusses all things related to tech with a focus on Android, iOS and mobile devices.

Calvin Roberts, is President & CEO of Lighthouse Guild.

Such a Pretty Girl

A Story of Struggle, Empowerment and Disability Pride

Nadina LaSpina, a disability rights activist tells the story of her liberation from oppressive standards of normalcy, showing that freedom comes not through cure, but through organizing to end exclusion from public and social life.
From the COVID-19 pandemic to the most active hurricane season on record, the challenges of 2020 remind us to be prepared for anything. This New Year’s Eve, kiss 2020 goodbye and resolve to be ready in 2021. This is an easy resolution that involves being informed, reviewing your preparedness plans and updating your emergency kit. For people with access and functional needs who rely on assistance from their caregivers, taking the following steps will help you and your support system develop an effective plan and be ready for any emergency.

1. Revise your emergency plan. Make sure your information is updated throughout the year, especially after a change. Be sure to record your caretakers’ information so they can be reached when needed. Your plan should include important information like allergies, medications (names, dosages, instructions), information on your medical conditions, dietary preferences, and daily routines. Read more at https://www.ready.gov/plan.

2. If you do not drive, discuss with your support system how you will leave the area if authorities tell you to evacuate. You can ask your local Emergency Management Office if transportation services are available for people with your disability during an emergency evacuation.

3. Sign up for state or local emergency alert system. Some states have specific alert systems for people with access and functional needs.

4. Store your important documents (i.e. Social Security card, birth certificate) in a safe, secured, waterproof place such as a locked safe with the documents sealed in waterproof bags. If you have any digital documents, you can store them on a secure, password-protected jump drive or in the cloud.

5. Take preparedness steps such as stocking up on food and household items to last for at least two weeks, storing a few weeks’ supply of over-the-counter medications and prescriptions, and having batteries for any essential medical equipment.

6. Learn where and how to use the controls for your water, electricity, gas and sewage system. Contact utilities company to tell them your needs especially if you have durable medical equipment.

7. If you haven’t started an emergency fund, start one immediately. It is extremely important to have spare cash on hand in case you find yourself displaced. Learn how to build your financial resilience at https://www.ready.gov/financial-preparedness.

8. Check your insurance plan to see if it covers all disasters – if not, consider another plan or enrolling in dual coverage. Make sure you have recent pictures of your home and property in case you must file a claim. You can add this to your waterproof document bag or stored in a password protect cloud or Iron Key thumb drive.

9. Talk to your support system about how they can help you and how you can reach them during an emergency. Show your support system how to use any medical equipment. Add what you discussed into your plan including any communication difficulties you may have.

10. Take a recent photograph of yourself, your loved ones and your pet(s) in case any of you should become separated during a disaster. Put copies in your important documents waterproof bag. Make sure your pet is included in your plans – find pet-friendly shelters, have your contact information listed on your pet’s collar, and update your pet’s microchip information if necessary. Learn more about pet preparedness at https://www.ready.gov/pets

11. Write out instructions for items and extra support that you will need during an emergency. This is highly recommended if you
When Patrick sits down to work on one of his verse novels, he enters a world of wonderment and mystery that puts him in control of the narrative unfolding through the pages. With the highs and lows, wins and losses, he knows the path of each character’s journey. But Patrick is still working on his own story, using each day as a learning experience on his journey to crafting his greatest masterpiece.

Since as far back as he can recall, the Missouri native struggled with fitting in among peers because of his autism. Often misinterpreted and misunderstood, he faced bullying throughout high school and was often made to feel like an outcast. With a strong support system of family, friends and recently his girlfriend, Britni, Patrick has cleared many hurdles to accomplish feats he wasn’t sure he’d ever reach.

Today, at 29, Patrick has a clear mind and has sighted set on achieving big things. He plans to release his seventh book, “Frost,” in September, a variety of scenarios, which makes me the go-to guy to call out plays in sports, main.

He knows his greatest masterpiece. When did you realize what it meant to be on the spectrum? How did that news impact your life? It was around the time I was in high school when I started to fully grasp that I was different. I started to understand why people didn’t understand me because I didn’t even understand myself.

How does your autism affect your life? How does it make you unique? My autism makes a lot of things challenging. On the other hand, it makes a lot of things better. I’m able to discern rhythms and patterns in a variety of scenarios, which makes me believe I am a better writer. Patrick’s story of perseverance to pursue his life’s work in the pages of his novels, shows that meaningful work can look different for everyone on the spectrum.

In celebration of the recent National Disability Employment Awareness Month, Autism Speaks interviewed Patrick with a number of questions.

At what age were you diagnosed with autism? I believe I was 12 or 13 years old when I was officially diagnosed.

What was the best advice you’ve ever received? The world doesn’t care. Find that personal support system and believe in the path you’ve chosen. You can’t control others, but you can change hearts and minds with your own actions and beliefs.

Why is advocating for yourself so important? Being a self-advocate is vital because in some cases you can’t help the way you are. Like I said, not everyone’s going to understand you, but that doesn’t mean you shouldn’t try to educate them and avoid a misunderstanding. Being true to yourself is the key to happiness.

What are a few of your personal goals for the future? Make it on a best sellers list! And complete my five-year plan to get four more book series out! Not to mention get married to the most beautiful woman ever, Britni! I’d also like to get off Supplemental Security Income (SSI), because I don’t wish to be reliant on government assistance forever. There are others who need it far more than me and I know I can survive without it.

FEMA REGION II

Continued from page 11 will not be able to carry your evacuation kit if you can’t remember everything you will need to do. Make sure to give a copy to your personal support network. You can also take pictures of your prescriptions and medical equipment, and label all of your medical equipment and supplies with your name.

12. Make sure to practice your evacuation routes multiple times. It is recommended that you practice with the lights off and with a flashlight. This will help you remember the route during an emergency.

Make preparedness a part of your routine in 2021. The steps above should be repeated throughout the year to ensure your plan is up-to-date and your emergency supplies have not expired. Additional resources are available. Please visit https://www.ready.gov/disability to learn more.

ACB Offers Film Review Contest for Kids

Blind and visually-impaired young people may compete in a Film Review contest sponsored by the American Council of the Blind’s Audio Description Project (ACB-ADP) and the Described and Captioned Media Program (DCMP). Students, aged 7 to 21, choose a film or video with audio descriptions from thousands of available titles. Films are available at www.dcmp.org or visit www.acb.org/adp/dvds.html for lists of DVDs and films with audio description.

There are four age categories. Reviews may be submitted in writing, in Braille or via an audio recording. Register for the contest at www.listeningislearning.org/badie.html.

Entries may also be submitted via e-mail or postal mail (submissions from outside the United States are fine) to ACB-DCMP Benefits of Audio Description In Education, 1703 N. Beauregard St., Suite 420, Alexandria, VA 22311 or jsnyder@acb.org. The deadline to enter is Jan. 22.

Contest winners in each category will be chosen by Feb. 19 and the grand prize winner will receive an iPad Mini. The first-place winners will receive a $100 iTunes gift card. Second-place winners will receive a $50 iTunes gift card, and third-place winners will receive a $25 iTunes gift card. Each supporting teacher who has a first-place winning student will be awarded a $100 Amazon gift card.
COVID VACCINE ADVISED FOR LTC RESIDENTS

The Alzheimer’s Association agrees with the recommendation by an independent advisory panel to the Centers for Disease Control and Prevention to prioritize residents and staff of nursing homes and other long-term care settings for the forthcoming coronavirus vaccines.

Forty-eight percent of nursing home residents are living with Alzheimer’s or another dementia, and the association has advocated strongly for greater access to PPE and rapid testing for residents and staff. Training and Protecting

TRAINING AND PROTECTING RIGHTS DURING PANDEMIC

Justice in Aging directing attorney Eric Carlson and senior staff attorney Natalie Kean recently presented a webinar for the National Center on Law & Elder Rights (NCLER) on recent Long-Term Services and Supports (LTSS) related changes that affect older adults and people with disabilities. The webinar, “LTSS Policy Changes in Response to COVID-19,” drew more than 1,300 law and aging advocates.

As the pandemic continues to impact older adults disproportionately, particularly those in congregate and institutional settings, this session provided important information to ensure that older adults and people with disabilities have access to critical support persons in hospital settings and can exercise their right to receive visitors in institutional settings.

Presenters also shared information about Medicaid changes to emergency eligibility protections, modifications to programs for home and community-based services, and vaccine distribution. The webinar may be seen at www.vimeo.com/481853738?

BRAIN SCREENING TODAY

It is important to get regular brain checkups like with other health screenings, such as cholesterol and blood pressure. Having a baseline and getting screened regularly helps identify potential memory problems sooner. Early diagnosis of all types of memory problems, including thyroid conditions, vitamin deficiencies, stress or Alzheimer’s allows one to begin treatment sooner and can improve quality of life.

The American Alzheimer’s Foundation (AAFA) provides free memory screenings in English and in Spanish every Monday and Wednesday, 10 a.m.-4 p.m. and Friday, 10 a.m.-2 p.m. Call 866 232-8484 to make an appointment.

FUN4THEDISABLED SEEKING VOLUNTEERS

Fun4theDisabled, is a group that celebrates what people with disabilities contribute to society. Its digital media provides a platform for people with disabilities to share their perspectives, learn about up-and-coming organizations and movements in the disability community, raise awareness of different disabilities, and most of all, celebrate them in ways that are fun.

Volunteers are needed in the following areas: advocacy, communication, fundraising, administrative support and video production.

The group’s mission is to create a community by, for and about people with disabilities, to help each other live their best lives. The organization provides videos and articles and conducts accessible events and activities and creates educational pieces about disabled experiences. If interested, email Vanessa Harris at fun@fun4thedisabled.com.

REGISTER FOR ONLINE MET SIGNS TOURS

Explore works of art through engaging conversations with Met experts in the museum’s Met Signs Tours, presented in American Sign Language without voice interpretation.

Dates include: The Birth and Life of Cubism with Emmanuel von Schack, Saturday, Jan. 23, 2 to 3:30 p.m. and The New British Galleries with Joyce Hom, Saturday, Feb. 20, 2 to 3:30 p.m.

Programs in ASL, without voice interpretation are intended primarily for the ASL community. ASL students may attend Met Signs tours with advance approval. Email access@metmuseum.org to register or request approval. Attendance sheets will not be signed.

FREE DEAF-BLIND WEBINARS FOR PARENTS AND TEACHERS

The National Center on Deaf-Blindness has posted a series of free recorded webinars for parents and teachers on instructional strategies for children and youth who are deaf-blind.

The archived webinars include Establishing Routines at Home; Academic Standards for Students with Significant Cognitive Disabilities; Early Literacy and Numeracy for Students who are Deaf-Blind; Meeting the Needs of Proific Communicators; and Accessing Grade Level General Education Curriculum. For more information visit www.deafchildren.org/2020/11/free-webinars-on-deaf-blind-strategies/.

HEALTH INSURANCE OPEN ENROLLMENT THROUGH JAN. 31

From now until Jan. 31, one can enroll for health insurance on New York State’s marketplace website. On the same website, one can check the family’s eligibility for children’s Medicaid or Child Health Plus.

Learn more, compare plans, and get enrollment help at www.ny stateofhealth.ny.gov/.

SCHEDULE YOUR FREE BRAIN SCREENING TODAY

The Alzheimer’s Association agrees with the recommendation by an independent advisory panel to the Centers for Disease Control and Prevention to prioritize residents and staff of nursing homes and other long-term care settings for the forthcoming coronavirus vaccines.

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MEET A COMPANION, PHONE FRIEND, PEN PAL, OR EVEN A SPOUSE

Professional man seeks nice lady for long term serious relationship. Please include phone number. Serious replies only.

SWM 71, looking for a phone friend. Male or Female.

A399

I am a pretty Asian American lady in her 50’s. I look Latin. 5ft 5 inches tall, looking for a pen pal or companionship with a man age 47 to 62 yrs., who likes museums, comedy clubs, board games, nature, art, music, talking and golf. I am college educated. Please provide phone number and photo.

A397

SWM, 56, wheelchair user, seeks single female 40-55 for friendship and more. Into baseball, fishing, comedy clubs. I live in Sayville, NY. I do not drive. Send photo and phone number.

A396

Senior Female, Nassau, looking for senior male to enjoy simple things in life, family, hugs, walking WHLI, Plattters.

A395

A God-fearing SMB, 41 seeking a God-fearing woman for long term relationship, and to spend the rest of my life with. I love going out to the movies and listening to music. I do not drive.

A394

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A108

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The Texas School for the Deaf football team has won the state championship in the TAPPS Division 1, six-man football championship with its first state title in the school's history, beating Veritas Academy, 63-32.

Blind Running Unity Day Connects Runners

Runners across the nation were recently informed that the 2020 California International Marathon was canceled due to health and safety guidelines associated with the COVID-19 pandemic.

For USABA runners and guides, it also meant the cancellation of the 2020 USABA Marathon National Championships, which are held in conjunction with the California International Marathon.

To fill the void left by the cancellation, USABA and marathon director Richard Hunter organized the first National Blind Running Unity Day presented by Allworth Financial, which took place on the scheduled date of the California International Marathon and USABA Marathon National Championships.

“One of the greatest things about the USABA Marathon National Championships is the community of runners who come together to encourage and motivate one another,” said Hunter. “Since the championships were canceled, it allowed us to pivot and be inclusive of more blind and visually impaired runners who would benefit from being part of this ever-growing community of running.”

With no registration fee, the premise of USABA’s National Blind Running Unity Day was to encourage visually impaired joggers and runners of all ability levels to lace up their shoes and go for a run, whether it was indoors on a treadmill or outside with a sighted guide.

The response was overwhelming. A total of 174 registrants from 30 states signed up to participate, and over 60 of those runners joined in two community Zoom sessions on Dec. 6, to share their experiences, encourage each other, and form a sense of community around the event.

There were so many great insights, suggestions, tips and tricks talked about on the Zoom calls that a USABA Running Club has been created on Strava to offer another connection point for blind and visually impaired runners and guides.

Driving the turnout were leads Hunter coordinated in nine cities: Boston, Chicago, Louisville, Nashville, Philadelphia, Phoenix, Sacramento, Seattle/Tacoma and Washington, D.C.

In total there were 174 registrants, including 91 blind runners, 62 guide runners and 21 volunteers representing 30 states.

USABA Updates Program Schedule

USABA has decided to suspend all in-person USABA programs through the end of February 2021 because of the ongoing COVID-19 pandemic. Namely, USABA’s annual winter sports events in Vermont and Colorado and USABA’s regional goalball tournaments typically planned for the start of the year have been canceled.

While this decision was not made lightly, USABA officials are hopeful that a clearer picture of the 2021 programming schedule will come into focus as further developments are made known regarding the COVID vaccine and other measures that would make an in-person event more feasible and safer than the current situation.

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Cindy Lou Altman and her guide dog Jada finished their 5k strong despite 35-degree temperatures and 30 mph winds in Coatsville, Pa.

Running Unity Day presented by Allworth Financial, which took place on the scheduled date of the California International Marathon and USABA Marathon National Championships.

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