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Chartered by the Congress of the United States

May 27, 2022

John E. Putnam
Deputy General Counsel
Department of Transportation

Submitted via regulations.gov

Re: Proposed Rulemaking on Accessible Lavatories on Single-Aisle Aircraft: Part 2, DOT-OST-2021-0137.

Dear Mr. Putnam:

Paralyzed Veterans of America (“PVA”) respectfully submits the following comment¹ to the Department of Transportation (“DOT” or “the Department”) regarding the proposed rule, “Accessible Lavatories on Single-Aisle Aircraft: Part 2,” (“Proposed Rule”).² We appreciate the Department’s efforts to address lavatory accessibility for all passengers with disabilities during air travel.

PVA is a congressionally chartered nonprofit organization. Since 1946, PVA’s mission has been to serve and advocate for military veterans with spinal cord injuries and disorders.³ PVA also carries out its mission through education and advocacy efforts.

One of the most important issues facing our members is access to air travel. We regularly work with airlines to improve the customer experience of paralyzed veterans traveling by air. PVA was a member of the Advisory Committee on Accessible Air Transportation (“Advisory Committee”) and the designated disability leader on accessible lavatories for that Committee. As the Department describes, this Committee’s consensus recommendations during the negotiated rulemaking process in 2016 led to the Proposed Rule, although after many years of delay.⁴

The Proposed Rule meets a pressing need to provide accessible lavatories on single-aisle aircraft, and the Department should finalize it promptly. Given the severity of the need and the Department’s delay in publishing this Proposed Rule, PVA encourages the Department to

¹ This comment letter was prepared with the assistance of Robin Thurston and Maher Mahmood, Democracy Forward Foundation.

² Accessible Lavatories on Single-Aisle Aircraft: Part 2, 87 Fed. Reg 17,215 (Mar. 28, 2022) (to be codified at 14 C.F.R. pt. 382).

³ *Our Mission & History*, PVA, <https://pva.org/about-us/mission-statement> (last accessed May 24, 2022).

⁴ 87 Fed. Reg at 17,215.

shorten the extended implementation timelines agreed to in 2016. Specifically, the Department should use its authority, to the extent possible, to subtract the six-year delay in promulgating the Proposed Rule from the deadlines for compliance, as doing so would be consistent with the understanding of the participants in the negotiated rulemaking. And the Department should reject any arguments for delay of implementation of the Proposed Rule based on cost or design because the costs of further delay outweigh any implementation costs.

Our comments below discuss the pressing need for accessible lavatories, the history of this rulemaking, why that history counsels in favor of shortened implementation timelines and responds to several of the Department's questions in the Proposed Rule.

1. There is a Pressing Need for Accessible Lavatories on Single-Aisle Aircraft.

As the Department observes, the fleets of the top eight U.S. domestic carriers largely consist of single-aisle aircraft.⁵ These aircrafts are now being used by airlines for an increasing number of long-haul flights—flights that can last upwards of four hours.⁶ There is still no federal requirement that these aircrafts have an accessible lavatory to accommodate individuals with mobility impairments. In 2019, of the top eight U.S. carriers, only 4.5% of their combined single-aisle aircraft fleet had accessible lavatories.⁷ Four of these carriers had no accessible lavatories in their single-aisle aircraft fleet at all.⁸ The Proposed Rule remedies this failing by requiring airlines to ensure that *at least one* lavatory on new certain single-aisle aircraft with 125 or more passenger seats is large enough to permit a passenger with a disability (with the help of an assistant, if necessary) to approach, enter, and maneuver within the aircraft lavatory, as necessary, to use all lavatory facilities, and leave by means of the aircraft's on-board wheelchair ("OBW").⁹

There is an urgent need for such a requirement. More than 25 million Americans with mobility issues, who may require accommodations when flying, stand to benefit from improved lavatory accessibility.¹⁰ These numbers will likely become greater as the U.S. population ages.¹¹ Many of these individuals rely on air travel for work, recreation, and to visit family and friends. But given the lack of accessibility requirements, lavatories may be unavailable to these millions of travelers while flying.

⁵ 87 Fed. Reg. at 17,219.

⁶ *Id.* at 17,216.

⁷ U.S. Gov't Accountability Off., GAO-20-258, Aviation Consumer Protection: Few U.S. Aircraft Have Lavatories Designed to Accommodate Passengers with Reduced Mobility 14 (2020), <https://www.gao.gov/assets/gao-20-258.pdf>.

⁸ *Id.*

⁹ 87 Fed. Reg. at 17,215.

¹⁰ *Id.* at 17,215–16.

¹¹ *Id.*

Lack of an accessible lavatory during a flight is uncomfortable, stressful, and can be psychologically damaging. Our members and other travelers who require accessible lavatories are forced to avoid bladder relief or bowel movements during their time on an airplane, which can last three to five hours or more. As our members have told us, this limitation forces them to take elaborate precautions to avoid having a bladder or bowel accident in flight, such as limiting food and fluid intake starting the day before flying, wearing catheters or protective undergarments during flights, and wearing dark clothing to mask any accidents. The problems caused by inaccessible lavatories have been so long-lasting that even our members' advocacy has begun to feel degrading. As one member expressed, it is undignified to have to repeatedly recount experiences where his lack of access to a lavatory resulted in accidents.

Traveling on a long-haul flight without access to a lavatory also risks physical harm. Holding bladder and bowel movements for an extended period of time can result in a urinary tract infection. The National Institute of Aging recommends that individuals should use the lavatory every 3-4 hours at a minimum because failing to do so can weaken the bladder muscles and make a bladder infection more likely.¹² Other risks include using a catheter in an unsanitary location like the airline seat to drain one's bladder. As one of our members explained, he was forced to use a catheter during a flight, and the flight attendants were dismissive of sanitation and privacy needs associated with catheter use; this refusal to provide basic assistance was humiliating to him.

Lack of accessible lavatories causes economic harm as well. Individuals often opt to avoid air travel and take a more time-consuming and costly means of transportation. For example, our members report driving instead of flying and selecting flights with layovers to avoid longer air travel. Some people adjust the timing of their travel plans to account for lack of access. The possibility of experiencing a bowel or bladder accident during a flight, which could lead to embarrassment and humiliation, is distressing. Others avoid travel altogether, which limits career opportunities, as well as personal relationships and recreation, not to mention the broader economic benefits resulting from travel-related spending.

Our members' experiences are typical of those in the broader disability community. PVA conducted an informal online survey with other veterans and disability rights organizations in fall of 2021.¹³ The survey gathered information on how to improve air travel for individuals with disabilities, including specific questions about barriers that exist when traveling by air.¹⁴ Over

¹² The National Institute of Aging is an institution part of the U.S. National Institutes of Health, helps the federal government in conducting and supporting research on the aging and health of older individuals. *See 15 Tips to Keep Your Bladder Healthy*, Nat'l Inst. on Aging (Jan. 24, 2022), <https://www.nia.nih.gov/health/15-tips-keep-your-bladder-healthy>.

¹³ *See* Ex. A, PVA, *Paraplegia News* June 2022, at 1.

¹⁴ *Id.* at 25.

56% of the nearly 1,230 respondents stated their decision to travel by air depended on accessibility of the aircraft's lavatory.¹⁵

The Government Accountability Office (“GAO”) identified similar concerns in a recent comprehensive report on “Aviation Consumer Protection, Few U.S. Aircraft Have Lavatories Designed to Accommodate Passengers with Reduced Mobility” (“Report” or “GAO Report”).¹⁶ Consistent with our members’ experiences, the GAO found that passengers with reduced mobility who need accessible lavatories take precautionary measures before flying, including severely limiting food and fluid intake in advance of the flight, thus “risking dehydration; using a catheter; or wearing a protective undergarment.”¹⁷ Others will avoid long travel by purchasing flights with connections or layovers.¹⁸ Still others will travel by car or not at all.¹⁹ The Report also discussed the anxiety and fear caused to passengers who rely on the OBW to get to the lavatory, because during the transfer, there is the possibility of having to deal with circumstances that are beyond their control.²⁰ Although the GAO Report provides important evidence of the kinds of concerns that passengers with disabilities face, we note that the absolute number of complaints identified in the GAO Report is almost certainly too low because savvy passengers understand that there is limited utility to complaining about inaccessible lavatories when that inaccessibility does not violate any requirements.

Accessible lavatories are a pressing need for millions of air travelers and potential air travelers. Finalizing this Proposed Rule promptly will provide numerous benefits, in the form of increased ease and dignity of travel for passengers with mobility impairments. It will also reduce the risk of medical complications from the extreme measures that are necessary to take a long-haul flight without lavatory access and increase the willingness to fly and the possibility of more flexible travel plans for passengers with mobility impairments. Increased willingness to fly will, of course, have attendant economic benefits, as well. The Proposed Rule thus responds to a pressing need and will bring the Department a significant step closer to providing equal travel opportunity to individuals with disabilities once aircraft are compliant.

2. The Proposed Rule’s Requirements Improve Accessibility of Lavatories.

Based on PVA’s experience and as agreed by the Advisory Committee, accessible lavatories require the following features²¹:

¹⁵ *Id.* at 26.

¹⁶ *See* Aviation Consumer Protection, *supra* n. 7.

¹⁷ *Id.* at 16.

¹⁸ *Id.*

¹⁹ *Id.* at 17.

²⁰ *Id.* at 16–17.

²¹ *Annex A: Aircraft Lavatories ACCESS Committee Agreed Term Sheet*, U.S. Dep’t of Transp. (Oct. 14, 2016), https://www.transportation.gov/sites/dot.gov/files/docs/Annex%20A.Lav_Agreed%20Text.pdf; *Facilitator Draft*

- The lavatory should be sufficiently spacious for a passenger with a disability to enter on an OBW with an attendant, if needed, and close the door.
- The passenger should be able to make a lateral transfer from the OBW to the toilet seat or be able to stand and pivot independently or with the assistance of an attendant.
- From a seated position, a passenger should be able to access flush controls, call buttons, and the lavatory door lock to ensure privacy.
- Passengers should be able to reach the sink to wash hands, use paper towels, and use the trash dispenser.
- The lavatory door sill should provide minimum obstruction to the passage of the OBW across the sill, while still preventing leakage of fluids from the lavatory floor and trip hazards during an emergency evacuation.

The Proposed Rule's requirements as to lavatory size meet these accessibility needs. The Proposed Rule is consistent with the consensus recommendations regarding retrofitting of the aircraft, requirements for new aircraft, and specifications for the OBW. The design will increase the footprint of the lavatory on single-aisle aircraft to permit a passenger with a disability (with the help of an assistant, if necessary) to approach, enter, and maneuver within the aircraft lavatory, as necessary, to use all lavatory facilities and leave by means of the aircraft's OBW.

3. The Department Should Shorten the Proposed Rule's Extended Implementation Times As a Matter of Equity.²²

Accessible lavatory technology is available from aircraft manufacturers, but "carriers do not choose to acquire this option for their single-aisle aircraft."²³ Carriers have made it clear that they will not provide accessible lavatories voluntarily. Finalizing this rulemaking promptly is necessary to make those aircraft accessible to travelers with mobility impairments. The Proposed Rule would require that the expanded lavatory sizes be implemented on qualifying aircraft: (1) that were initially ordered 18 years after the effective date of the final rule implementing the negotiated rulemaking agreement; or (2) that were delivered 20 years after the effective date of such a final rule; or (3) for which an application for a new type-certificate is filed after 1 year from the effective date of the final rule. These terms are consistent with those agreed to in the negotiated rulemaking six years ago.

Term Sheet-Aircraft Lavatories Co-Chair Mark-up, U.S. Dep't of Transp. (Oct. 14, 2016), https://www.transportation.gov/sites/dot.gov/files/docs/P6.Lav_Agreed%20Text.pdf.

²² PVA stands by its commitment to the terms of the negotiated rulemaking, including "not to take a position materially inconsistent with the Term Sheet during the public comment period of the proposed rule to the extent that the proposed rule has the same substance and effect as the Term Sheet," but, as discussed, the timing of this NPRM is not consistent with the expectations of the negotiated rulemaking. *ACCESS Committee Ground Rules*, U.S. Dep't of Transp. (May 24, 2016), <https://www.transportation.gov/office-general-counsel/negotiated-regulations/access-committee-ground-rules>.

²³ Aviation Consumer Protection, *supra* n. 7.

The Department first proposed conducting a negotiated rulemaking concerning accommodations for air travelers with disabilities regarding several issues, including accessible lavatories in 2015.²⁴ In May 2016, the Department established the Advisory Committee on Accessible Air Transportation to negotiate and develop a proposed rule.²⁵ Its members included PVA, other disability rights organizations, and representatives of major airlines and aircraft manufacturers.²⁶ During the first meeting, and as noted in the Committee’s Ground Rules, the Department informed the Advisory Committee that if it came to a consensus on the terms of the proposed rule, the Department “*would act in good faith to issue a proposed rule that reflects those terms as closely as possible.*”²⁷

From May 2016 to November 2016, the Advisory Committee met six times. PVA was the designated disability leader for accessible lavatories. PVA worked diligently with the facilitators and other Advisory Committee members, including disability advocates, air carriers, and original equipment manufacturers (“OEMs”) to reach consensus on accessible lavatory requirements, including the time frame for implementation. After extensive negotiations, the members of the Committee reached a compromise on implementation times. While PVA and other disability advocate members had pushed for a ten-year implementation deadline, they ultimately agreed to the longer timeframes for implementation (aircraft ordered 18 years after the effective date of any final rule or delivered 20 years after that same date) to ensure that the rulemaking proceeded. PVA agreed to the lengthy implementation timeframe determining it was better to have a date certain for access rather than continuing to dispute whether or not lavatories should even be accessible.

During this time, PVA and the other Advisory Committee members had reason to expect that a Proposed Rule would be published almost immediately after the Advisory Committee finalized its recommendations. Indeed, in July 2016, during the height of the negotiations, Congress enacted the FAA Extension, Safety, and Security Act of 2016 (“FAA Act of 2016”), which directed the Department to move forward with the rulemaking within one year.²⁸ The Committee adopted its final resolution in November 2016.²⁹ But the Department did not move forward with

²⁴ See Nondiscrimination on the Basis of Disability in Air Travel; Consideration of Negotiated Rulemaking Process, 80 Fed. Reg. 75,953, 75,953 (Dec. 7, 2015) (to be codified at 14 C.F.R. pt. 382).

²⁵ Nondiscrimination on the Basis of Disability in Air Travel: Negotiated Rulemaking Committee Membership and First Meeting, 81 Fed. Reg. 26,178 (May 2, 2016) (to be codified at 14 C.F.R. at 382).

²⁶ *Id.* at 26,179; see also *ACCESS Committee Members*, U.S. Dep’t of Transp. (June 3, 2017), <https://www.transportation.gov/office-general-counsel/negotiated-regulations/access-committee-members>.

²⁷ 87 Fed. Reg. at 17,215.

²⁸ FAA Extension, Safety, and Security Act of 2016, Pub L. No. 114-190, § 2108, 130 Stat. 615, 622 (2016), Add.2; see also U.S. Dep’t of Transp., *Report on Significant Rulemakings* at 88 (June 2015), <https://www.transportation.gov/regulations/2015-significant-rulemaking-archive>.

²⁹ U.S. Dep’t of Transp., *Resolution of the U.S. Department of Transportation ACCESS Committee* (Nov. 22, 2016), <https://www.transportation.gov/sites/dot.gov/files/docs/ACCESS%20Committee%20Final%20Resolution.11.21.16.pdf>.

the rulemaking as required by Congress. Instead, it delayed the process and moved the accessible lavatories rulemaking to its Spring 2018 long-term agenda.³⁰ Its Fall 2018 regulatory agenda then removed the rulemaking entirely. In November 2018, PVA filed a lawsuit challenging the Department's unlawful delay in promulgating this accessible lavatory rule.³¹ Specifically, PVA requested the Court to order the Department to comply with its statutory authority to issue the rulemaking on accessible lavatories.³² In June 2019, the Department announced that it would move forward with a rulemaking on more limited accessibility issues, but would only request additional information on lavatory size, despite its earlier commitments to the contrary.³³ It was not until the current Proposed Rule, published nearly six years after the Advisory Committee's consensus recommendation, that the Department met its obligation to move forward with the lavatory accessibility rulemaking.

None of the entities involved in the negotiated rulemaking could have foreseen such excessive delay, and all should have reasonably expected the compliance deadlines to have begun running several years ago. But as the Department observes, the negotiated rulemaking term sheet ties compliance dates to any final rule.³⁴ Nevertheless, the Department should exercise its authority, to subtract the nearly six-year delay in promulgating the Proposed Rule from the 18- and 20-year time frames agreed to by the Advisory Committee. Doing so is necessary to meet the Department's accessibility obligations to air travelers with disabilities. As the Department observes, it is "the affirmative responsibility of the Federal Government to advance equity, civil rights, and equal opportunity for all individuals, including individuals with disabilities."³⁵

Air carriers can hardly complain about a shortened time frame. Many major carriers participated in the negotiated rulemaking and agreed to compliance deadlines that should have gone into effect years ago. They have been on notice since 2016 that an expanded lavatory size was coming, and they have had the intervening years to prepare to come into compliance. Considering the excessive delays in publishing the Proposed Rule, PVA encourages the Department to reassess its obligations to ensure a more equitable timeframe for implementation. The millions of individuals with mobility issues stand to benefit.

³⁰ See U.S. Dep't of Transp., Accessible In-Flight Entertainment and Accessible Lavatories on Single-Aisle Aircraft, RIN 2105-AE32 (published in Off. of Info. & Regul. Affs., Spring 2018 Unified Regulatory Agenda), <https://www.reginfo.gov/public/do/eAgendaViewRule?pu-bId=201804&RIN=2105-AE32>.

³¹ See Press Release, PVA, Ahead of Travel Holiday, Paralyzed Veterans of America Seeks Order Compelling Department of Transportation to Release Rules on Airplane Restroom Accessibility (Nov. 28, 2018) available at <https://pva.org/news-and-media-center/recent-news/ahead-of-travel-holiday-pva-seeks-order-compellin/>.

³² *Id.*

³³ Democracy Forward Found., *Paralyzed Veterans of America et al. v. Department of Transportation, Status Report* (7/5/2019), <https://democracyforward.org/wp-content/uploads/2018/12/20190705-PVA-Gov-status-rpt.pdf>.

³⁴ U.S. Dep't of Transp., *Facilitator Draft Term Sheet*, *supra* n. 21.

³⁵ 87 Fed. Reg. at 17,215.

4. The Department Should Not Delay the Implementation of the Proposed Rule in Response to Cost or Design Concerns Raised by Airlines or Aircraft Manufacturers.

During the negotiated rulemaking, airlines and aircraft manufacturers advocated for extended compliance deadlines based on their claimed costs of implementation. We are concerned that they will do the same in response to the Proposed Rule. The Department should reject any such arguments, which are based on potential revenue loss, and instead shorten compliance deadlines, as discussed above. Under no circumstances should the Department further delay the proposed extended compliance dates.

There is good reason to believe that the potential revenue loss predicted by airlines during the negotiated rulemaking was too high.³⁶ That revenue loss assumed the increased lavatory size would take up space usually filled by a row of three seats. This is likely an overestimation as it assumes that every seat will be filled by a passenger—an assumption that is inconsistent with any argument by airlines about reduced demand for travel.

As DOT observes, carriers with the largest percentage of accessible lavatories in their fleets tend to be low-cost carriers with fewer requirements for galley space.³⁷ Low cost and ultra-low-cost carriers compete effectively with traditional flagship carriers, despite this limited galley service. These include Frontier Airlines³⁸ and Spirit Airlines,³⁹ which compete primarily based on cost. Indeed, these carriers continue to lead U.S. airlines in capacity growth despite their higher percentage of accessible lavatories.⁴⁰ And Delta Airlines acknowledged that its biggest competition in domestic operations is pricing from lower-cost carriers.⁴¹ The success of these

³⁶ 87 Fed. Reg. at 17,220–21.

³⁷ 87 Fed. Reg. at 17,218.

³⁸ Frontier Airlines, *U.S. SEC Form 10-K* at 8 (Feb. 23, 2022), <https://ir.flyfrontier.com/static-files/077f284b-d1ec-4fa5-a48a-4702296e877e> (Frontier Airlines’ SEC annual filing, notes the competition advantage it has over American Airlines, Delta Air Lines, United Airlines, and Southwest airlines is their “low-cost structure, low base fares and [their] focus on the leisure traveler.” Their low-cost structure allows them to price the fares at a level where they can be profitable as compared to the bigger carriers.)

³⁹ Spirit Airlines, *U.S. SEC Form 10-K* at 9 (Feb. 8, 2022), <https://sec.report/Document/0001498710-22-000088/> (Spirit Airlines SEC annual filing status indicates: “We typically compete in markets served by traditional network airlines, and other low-cost carriers and ULCCs, and, to a lesser extent, regional airlines.” They further discuss, “...our principal competitive advantage is our relative cost advantage which allows us to offer low base fares profitably. In 2021, our unit operating costs were among the lowest in the U.S. airline industry. We believe our low unit costs coupled with our relatively stable non-ticket revenues allow us to price our fares at levels where we can be profitable while our primary competitors cannot.”)

⁴⁰ Airlines for America, *Data & Statistics – Impact of COVID-19: Data Updates* (May 25, 2022), <https://www.airlines.org/dataset/impact-of-covid19-data-updates/>.

⁴¹ Delta Airlines, *U.S. Form 10-K* (Feb. 11, 2022), <https://app.quotemedia.com/data/downloadFiling?webmasterId=90423&ref=116450628&type=PDF&symbol=DAL&companyName=Delta+Air+Lines+Inc.&formType=10-K&formDescription=Annual+report+pursuant+to+Section+13+or+15%28d%29&dateFiled=2022-02-11&CK=27904>.

low and ultra-low-cost airlines over recent years strongly suggests that robust galley services are not essential for airlines to succeed in the current market.

Nor should DOT extend compliance dates in response to complaints by airlines about the general state of the air travel industry. Airlines for America recently reported that the airline industry is steadily improving especially as to domestic air travel (which is most relevant to single aisle aircraft).⁴² And, of course, the airlines received massive financial support from the government during COVID-19 pandemic,⁴³ more than any other industry impacted by COVID-19.⁴⁴

5. Responses to the Department's Questions.

We provide the following answers to the specific questions from the Department.

a. Should the Department Adopt a Different Tiered or Phased Model for Implementation?

Although we agree that the Department may choose to adopt a different tiered or phased model than the one outlined in the Proposed Rule, the final rule should not further delay complete implementation, given the pressing need for accessibility. The Department should not adopt different implementation requirements for different sizes of carriers or aircrafts, aircrafts used for longer routes or aircrafts used for routes that are busier than others. This type of differential treatment would burden passengers because they would have to determine which flight routes or aircrafts have accessible lavatories. Inconsistent application of the accessible lavatory requirement within an airline's fleet is problematic because substitutions in airplanes, if a flight is delayed, changed, or canceled, will leave passengers without an accessible lavatory. Without assurance that the airplane will be accessible, passengers will be obliged to go through the onerous and dangerous precautions discussed above.

b. Should the Department Adopt Alternative Performance-Based Standards, Such As Requiring Only a Certain Percentage of a Carrier's Flights Between City-Pairs to Have Accessible Lavatories?

PVA does not support an alternative performance-based approach such as requiring only a certain percentage of a carrier's flights between city-pairs to have accessible lavatories unless it is a *temporary* measure. Passengers who need an accessible lavatory cannot always be flexible in their travel dates and times, so for situations where there is an aircraft change or cancellation – the individual may still be forced to delay bodily needs on the flight. All larger single-aisle

⁴² Airlines for America, *supra* n. 40.

⁴³ Office of Inspector General, *CARES Act*, <https://oig.treasury.gov/cares-act> (last updated Jan. 15, 2021).

⁴⁴ Andrew Ross Sorkin, *Were the Airline Bailouts Really Needed?*, New York Times (Mar. 16, 2021), <https://www.nytimes.com/2021/03/16/business/dealbook/airline-bailouts.html>.

planes should have accessible lavatories to protect passengers and meet the Department's equity obligations.

c. To What Extent Do Accessible Lavatories on Twin-Aisle Aircraft Meet the Needs of Passengers With Disabilities, Particularly Passengers With Mobility Impairments? Are Accessible Lavatories on Twin-Aisle Aircraft Large Enough to Accommodate an Assistant to Assist the Passenger With Transfers Between the OBW and the Toilet?

Twin-aisle aircraft are required to have one accessible lavatory, large enough to accommodate a passenger on the OBW behind a closed door. The experience of passengers with disabilities in using these lavatories is varied. One PVA member recalled that of the two accessible lavatories on twin-aisle aircraft that he recently accessed, only one was large enough to accommodate both the OBW and his caregiver, who assisted him with the transfer. The other lavatory was unable to accommodate him and his caregiver because the door style was a folding door, not a sliding door. Typically, a sliding door provides more room to the passenger and caregiver. This member also noted that the OBW in one case did not have brakes which made transfers difficult.

Others describe the accessible lavatories as very small and potentially dangerous for individuals with disabilities because of the lack of room for assistants and unsafe OBWs. One member could not access the lavatory on the OBW because the door was not wide enough for him to enter the lavatory. Lack of an accessible lavatory on a twin-aisle aircraft is a violation of federal regulations.⁴⁵ It is imperative that the lavatory design uphold the performance standards to provide meaningful access.

d. If It Is Feasible to Install Lavatories That Are Large Enough to Accommodate a Person With a Disability Unassisted on an Earlier Schedule Than Lavatories That Are Large Enough to Accommodate a Person With a Disability Assisted and Unassisted, Would That Be More Beneficial to Persons With Disabilities? Why or Why Not?

The current time frame for fully accessible lavatories on larger single-aisle aircraft is decades long. The Advisory Committee initially considered multiple phases prior to full accessibility and ultimately narrowed them to two tiers, short-term and long-term. The Department should ensure complete implementation in the Proposed Rule. Airlines have been aware since at least 2016 that

⁴⁵ 55 Fed. Reg. 8008 (Mar. 6, 1990) (codified as amended at 14 C.F.R. § 382.63) (An “accessible lavatory” with respect to twin-aisle aircraft must permit a qualified individual with a disability to enter, maneuver within as necessary to use all lavatory facilities, and leave, by means of the aircraft’s on-board wheelchair; must afford privacy to persons using the on-board wheelchair equivalent to that afforded ambulatory users; and must provide door locks, accessible call buttons, grab bars, faucets and other controls, and dispensers usable by qualified individuals with a disability, including wheelchair users and persons with manual impairments.)

they need to move toward providing fully accessible lavatories on larger single-aisle aircraft. There is no reason to further delay lavatory access.

6. Conclusion.

Lack of accessible lavatories poses significant difficulties and risks for individuals with disabilities. While we fully support the Department's effort to provide accessible lavatories for individuals with disabilities, we believe any further delay to the implementation of this Proposed Rule is unreasonable. The disability community, including PVA members, have waited over 30 years for accessible flights, and did not expect a delay in implementing the compromises agreed to in 2016. There is a pressing need for this rule and the history of the rule and negotiated rulemaking favors a shorter implementation timeline. We encourage the Department to proceed with finalizing the Proposed Rule so that all individuals can travel with dignity and safety on covered commercial aircraft.

Thank you for the opportunity to provide comments on this important matter. If you have any questions, please contact Heather Ansley, Associate Executive Director of Government Relations, with PVA by email at heathera@pva.org or Lee Page, Senior Associate Advocacy Director, with PVA by email at leep@pva.org.

Sincerely,

A handwritten signature in black ink that reads "Heather J. Ansley". The signature is written in a cursive, flowing style.

Heather Ansley
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EXHIBIT A

PARAPLEGIA NEWS JUNE 2022

PN

Restoring Movement

Targeted spinal-cord stimulation shows potential

Testing MagTrack

Drive a power chair with facial expressions



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PVA advocates for more accessible air travel

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IMPACTING LIVES THROUGH SCIENCE: Funding Research to Improve Life After SCI/D

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Paralyzed Veterans of America Spinal Cord Injury Research Foundation funds grants to promote innovative research to find treatments and cures for paralysis, support efforts to improve lives of individuals living with SCI/D, and fund SCI/D Fellowships to encourage young researchers to specialize in the area of spinal cord research.

Awards will be made in November 2022 for the funding period
January 1, 2023 – December 30, 2024.

Research Grants: Up to \$150,000 (two years)

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PROPOSALS ARE ACCEPTED IN THE FOLLOWING AREAS:

- | | |
|---|-----------------------------|
| ■ Basic Science | ■ Clinical Applications |
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Assistive Technology | ■ Post-Doctoral Fellowships |

Grant application period opens **April 1, 2022.**

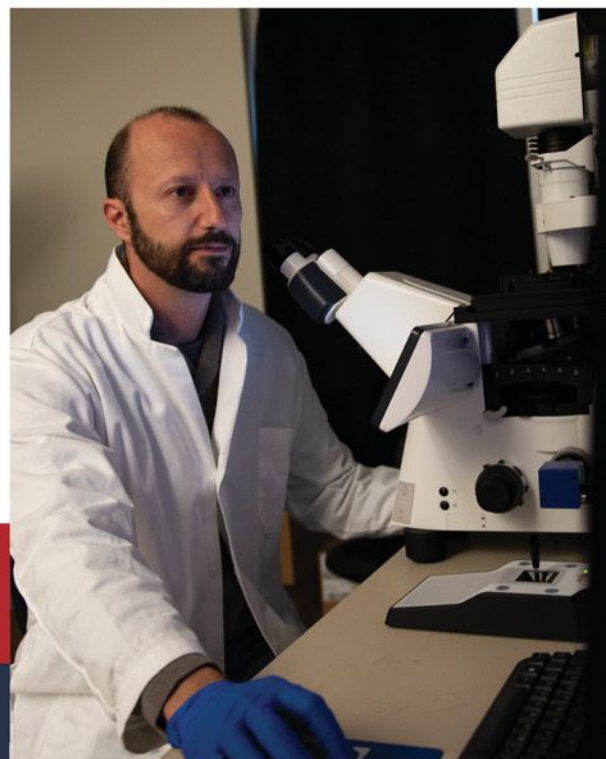
All applications must be submitted online by **July 1, 2022.**

Apply at: <https://pva.aibs-scores.org>

Late applications will not be accepted.

For additional information, contact:

Lindsay Perlman | 202.416.7611 • LindsayP@pva.org



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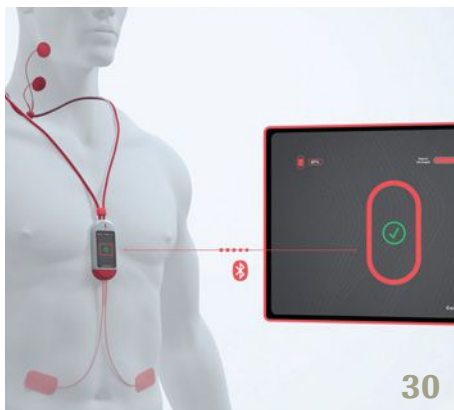
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ON THE COVER

Paralyzed Veterans of America is still fighting for improved access to air travel for passengers with disabilities decades after the Air Carrier Access Act's passage.

Getty Images/Issarawat Tatong

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FEATURES

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by Brittany Martin

With a TV show, website database, certification program and more, Becoming RentABLE is making vacation rentals more accessible for everyone.

30 A Stimulating Walk

by Brittany Martin

Researchers are working to improve quality of life and restore locomotion in people with SCI using purpose-built electrical stimulation devices.

24 Flight Plan

by Heather Ansley, Esq., MSW

From advocacy to surveys to websites, PVA is continuing its fight to improve air travel for all passengers with disabilities.

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"The development of our wearable
alternative controller eliminates
the need for having multiple
assistive technologies, replacing
them with a single multimodal and
integrated system." — Nordine Sebkhi

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Now in its 76th year and the official publication of Paralyzed Veterans of America, *PN* is a national, monthly magazine that covers news, health, research, lifestyle and issues of interest and concern to veterans and others with spinal-cord injury and disease. Anyone interested in submitting an article to *PN* should consult the Contributors Guidelines found on our website at pnonline.com. *PN* neither endorses nor guarantees any of the products or services advertised in the magazine. Readers should thoroughly investigate any product or service before making a purchase.

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JUNE Editor's DESK

The summer travel season is upon us, and while many people will be traveling to fun destinations by air, I'm one of those who prefers to drive — even if it's across the country.

As a Navy veteran who flew often, I'm certainly not afraid of flying. But I do have serious concerns about how my wheelchair and I are treated by the airlines. I'm far from alone in my air travel misgivings. Paralyzed Veterans of America (PVA) has been a key leader in the effort to make air travel better for people with disabilities for the better part of 40 years.

You're going to read a lot about the problems people with disabilities have while flying and PVA's efforts to improve that experience in this issue. PVA National President Charles Brown gives his personal take on the troublesome situation in *PVA From The Top* (page 8). *On The Hill* (page 13) looks at PVA's ongoing efforts to make changes to air travel on Capitol Hill. And the main feature article this month, *Flight Plan* on page 24, offers a deep take on flying with a disability, including the not-so-surprising results from a survey PVA conducted.

All of PVA's efforts to making flying safer and more comfortable for everyone is just another reason why it's such a great organization.

We hope you enjoy those articles and all of this month's issue.



Tom Fjerstad, Editor-in-Chief

contributing to this issue...



**Heather Ansley,
Esq., MSW**
(p. 24)



Danica Gonzalves
(p. 13)

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PVA CHARLES BROWN NATIONAL PRESIDENT from the TOP

Bare Accessibility

As the summer travel season kicks into full gear this month, many families start thinking about getaways to sunny beaches, beautiful mountains, historic sites or visits with faraway family and friends.

Most of those folks' travel to their destination of choice will simply involve choosing whether to take a car, plane or train. There's not much trouble to worry about with any of those choices, as they've become such a regular part of life for the majority of the world.

Flying is a popular and fast way to travel, so you don't miss too much of that coveted vacation time. Unfortunately, that mode of transportation comes with great fear for those of us with disabilities.

That's right — flying can lead to bad anxiety and fear for many travelers with disabilities. Why, you ask?

Because when traveling by air with a disability, you must put faith in the system of transportation that demands you be lifted from your mobility device onto an aisle chair that's no wider than 13 inches, be pulled down the narrow aisle of an airplane and then be lifted into a seat that doesn't offer proper support.

Meanwhile, your personal mobility device, which has been made specifically for you to give proper support and prevent injuries, is taken away and put into the cargo area with other luggage or equipment stacked around it.

Your mobility device is often beaten, damaged or destroyed by the crews who inadvertently put the wrong things around it or even improperly secure it inside the cargo area. It's sometimes dropped from the conveyor belt or even crushed by the closing and opening of the cargo door. What's even worse is sometimes your mobility device is left behind and lost somewhere.

I think it's easy to see why someone with a disability would have anxiety about air travel.

I think it's easy to see why someone with a disability would have anxiety about air travel.

Some people say you also have to get out of your mobility device when traveling by car, but that's not always the case. There are vehicles adapted so you can travel in your mobility device and remain in a safe and comfortable environment. You can ride a bus and stay in your mobility device. You can ride a train in your mobility device.

Air travel is the only transportation mode that demands you get out of your mobility device and subject your body or device to additional damage.

In 1986, Congress passed the Air Carrier Access Act (ACAA). It's a law that says air travel must be accessible and safe for passengers with disabilities. In all the years since, the airlines have done nothing to improve on safety for passengers with disabilities. In fact, they really have done nothing to make the inside of aircraft accessible.

In 1990, Congress passed the Americans with Disabilities Act (ADA). This is where many people get confused. If the ADA and its broad laws make public establishments and transportation modes accessible, why leave out air travel?

The answer is simple: Congress had already mandated that air travel be made accessible with the ACAA. What it didn't do in either the ADA or ACAA was create a continued effort to make disabled air travel better with every new aircraft design. Basically, airlines can keep the same bad interior layout and the accessibility to the barest form.

How many new aircraft have been designed since 1986? How many new interiors have been designed and built? The answer is many. Have any of them ever been designed with complete accessibility in mind? No. That's completely unacceptable.

When I started this article, I was speaking about families enjoying their summer vacations. The unfortunate truth is many families or friends won't be able to enjoy life like the rest of the world. They'll be limited on how they can travel by an industry that has done little to make accessibility a priority.

Please join me in fighting for accessible air travel for everyone by visiting pva.org/airtravel. ■

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reasons & remarks

TOM FJERSTAD,
EDITOR

A Lot To Offer

When I think of June and Paralyzed Veterans of America (PVA), I think of a great picnic.

Prior to becoming part of the team at PVA Publications, I was president of the PVA Minnesota Chapter, where I've been a member since the chapter's inception in 1993. June was always the month the chapter held its annual picnic. This was a great time to connect with other chapter members and spinal-cord injury/disease health care professionals from the Minneapolis Department of Veterans Affairs Health Care System in an informal setting.

The Minnesota Chapter is far from unique in sponsoring similar opportunities for members and guests. Whether it's picnics, annual membership banquets, tickets to sporting events, bowling, trapshooting, fishing or simply reimbursement for a trip to a favorite restaurant for dinner, PVA's chapters have a lot to offer.

I took a quick glance at some of the chapters' event calendars in their newsletters to see what's happening in the coming months. Here are a few examples:

- The Cal-Diego Chapter offers sailing with Challenged Sailors San Diego. The outings are available in July, August and September.
- The Great Plains Chapter has a full gym and fitness center located in its office with a multitude of programs.
- The Kentucky-Indiana Chapter has a bowling tournament scheduled in August at Kingpin Lanes in Louisville, Ky.
- The Oregon Chapter offers a deep sea fishing outing in July.
- The Vaughan Chapter in Chicago has a bocchia ball tournament set for June 11–12.
- The Wisconsin Chapter holds its annual trapshoot in Green Bay, Wis., June 10–12.

I've participated in the Wisconsin Chapter trapshoot in the past, and I can tell you that novice shooters are always welcome, and the serious competitors there love introducing

someone new to the sport. I can personally attest to this, as the first time I tried trapshooting was at this event.

I didn't have a gun at the time, so one of the participants let me borrow one. I did so well that I won the low-shooter award. And as a prize, I was given a box of shells and told to go home and practice!

The Wisconsin Chapter also will sponsor a salmon fishing outing on beautiful Lake Michigan in July. I grew up fishing almost every weekend in Minnesota — yes, even in the winter. Ice fishing isn't something I've done since joining the wheelchair club, and I don't know of any chapters that offer it. But if you wanted to give it a try, I'm sure there are people at a PVA chapter who would help you.

The Minnesota Chapter has a weeklong fishing event in August this year to be held at Veterans on the Lake Resort in Ely, Minn. The resort's cabins are wheelchair-accessible, and some even have roll-in showers. I used to spend a week at this resort every summer when I lived up there and may seriously consider a return trip soon to escape the Phoenix area's notorious 100-plus-degree summer heat.

If trapshooting or fishing aren't your things, then maybe shooting a little pool will be more your style. Wheelchair billiards tournaments are extremely popular. And if one isn't happening near you, it may be a good excuse for a road trip.

I apologize if your chapter has an event that you think is outstanding or unique and I didn't mention it. There's so much going on, it would be impossible to mention it all in this column.

From archery to wheelchair yoga, whatever your interest, you can find something fun to do near you. We always have a PVA calendar of events in each issue of *PN*. Make sure to check it out to see if something you're interested in is happening near you. Better yet, reach out to one of the local PVA chapters and ask what it has happening this summer. A list of PVA's chapters and contact information can be found on page 9.

Stay healthy, and enjoy your summer. ■

From archery
to wheelchair
yoga, whatever
your interest,
you can find
something fun
to do near you.

Remembering Fred Cowell

An uncompromising advocate for the disabled community and veterans' health care are just some of the accolades being offered when speaking about late-Paralyzed Veterans of America (PVA) Executive Director Fred Cowell.

A Navy and Vietnam War veteran, Cowell passed away of natural causes March 5 in Fort Washington, Md. He was 80.

Cowell made a strong impact with PVA. After being a member of the PVA Gateway Chapter, he was hired in 1989 as PVA's national director of advo-



COURTESY OF PARALYZED VETERANS OF AMERICA



Fred Cowell, pictured at left and above far right, passed away March 5 in Fort Washington, Md., at age 80.

COURTESY OF PARALYZED VETERANS OF AMERICA

cacy and led the organization's efforts to secure passage of the Americans with Disabilities Act.

He later became PVA's executive director and helped lead the organization through a major restructur-

ing and renovation of its national office building.

Cowell also served as a senior health policy analyst and concluded his two-decade career with PVA as director of its research and education program.

A highly respected and regular speaker on Capitol Hill, Cowell delivered numerous congressional testimonies on PVA's behalf and served on several federal advisory committees.

Born in East St. Louis, Ill., Cowell was also a talented artist. He mastered stained glass artwork while recovering from a spinal-cord injury in the St. Louis Department of Veterans Affairs hospital and later opened a shop featuring his artwork and that of other local artists.

Cowell was laid to rest at Jefferson Barracks National Cemetery in St. Louis. 

Pat's Run



CHRISTOPHER DI VIRGILIO

Staff and family members from the Paralyzed Veterans of America (PVA) Arizona Chapter and PVA Publications joined together to take part in the 18th annual Pat's Run April 23 in Tempe, Ariz. The 4.2-mile run honors the life of late Army veteran Pat Tillman, who played for Arizona State University's football team and left a standout career with the NFL's Arizona Cardinals in 2002 to enlist in the military following the 9/11 terrorist attacks. Assigned to the second battalion of the 75th Ranger Regiment, Tillman was killed in action in eastern Afghanistan April 22, 2004.

Great Roll



Paralyzed Veterans of America (PVA) Colonial Chapter members hit the streets of Annapolis, Md., April 2 for a scavenger hunt as part of PVA Awareness Month. The Great Roll saw 16 chapter members using clues to navigate a course through Maryland's capital city. Six volunteers ran stations along the course, where participants took part in mental challenges to acquire stamps, with the winner receiving a \$500 Visa gift card. 🚶‍♂️



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Addressing Ongoing Travel Barriers

Paralyzed Veterans of America

(PVA) members often encounter barriers of various kinds when attempting to travel for vacation, to visit family or take trips for work.

Unfortunately, the barriers are not limited to the airplane. Other common barriers encountered include difficulty moving within the airport; accessing ground-based airport transportation, including shut-

ILLUSTRATION BY ANN GARVEY



tles; securing adapted rental cars; and locating accessible hotel beds.

The Air Carrier Access Act (ACAA) prohibits discrimination in air travel, but the Americans with Disabilities Act (ADA) governs the airport's services and design. Airport services must be accessible for individuals with disabilities, including wheelchair users. For example, if the airport offers shuttle or transportation services, such as trains between terminals or parking, the transit must be accessible.

Public Transportation, Taxis & Ridesharing

Transportation from the airport to your destination may be required to be accessible or provide alternative options. Public transportation, such as



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city buses or trains, must offer accessible services. If the general mode of transportation is not accessible, paratransit services must be available. Even shuttles that run between the airport and a private hotel must be accessible.

Although the ADA prohibits discrimination by private companies primarily engaged in transportation, private taxi companies are not required to have accessible cars. However, they cannot discriminate against individuals who can physically use the vehicle. For instance, a taxi driver cannot refuse to assist with the stowing of mobility devices or charge higher fares.

Rideshare services, such as Uber and Lyft, must also adhere to the ADA, but the companies have been found to have discriminatory practices for passengers with disabilities.

The Department of Justice (DOJ) has determined that Uber's "wait time" fees were discriminatory. Uber

imposes fees, in some locations, after two minutes of when the car arrives. Many individuals with disabilities need more time, however, to enter the vehicle. The DOJ found that Uber failed to ensure adequate boarding time, equitable fares and make reasonable modifications to its policies and practices.

Rideshare companies are also required to train their drivers in assisting individuals with disabilities. The DOJ settled a case with Lyft when it failed to do so.

Still, rideshare companies do not have sufficient, or any, accessible vehicles in many areas. Several lawsuits are pending in the courts to address this issue.

Rental Cars

Some travelers may choose to rent a car. When renting a car, special vehicle modifications may be needed, such as installation of hand controls.

Under the ADA, rental car companies must accommodate individuals with disabilities, including offering hand control options. The companies are not required to provide adaptive equipment on all vehicle types but should employ best efforts to accommodate the vehicle type requested.



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Even individuals who are not licensed drivers can rent a car if accompanied by a licensed driver who meets minimum qualification requirements, i.e., a certain age. But most companies don't offer the option of reserving an adapted vehicle online and require calling the company ahead of time.

As noted previously, when rental car companies or airports provide shuttle bus services, they must offer accessible shuttles; however, many travelers often find that such services are not provided or there may be lengthy delays. The DOJ has already reached settlements with major rental car companies, including Alamo Rent-a-Car, National Car Rental System and Avis Rent-a-Car, involving shuttles.

Hotel Accessibility

Upon arriving at their hotel, many wheelchair users find that access barriers continue.

Hotels must offer accessible rooms, but the number of accessible rooms required depends on the hotel's size.

For large hotels with 501 to 1,000 rooms, only 3% must be accessible for individuals with mobility disabilities and only 1% must have roll-in showers. This means a hotel with 900 rooms is only required to have 27 accessible rooms and nine with roll-in showers. Due to the minimal requirements, accessible rooms are often in short supply.

Even "accessible" rooms may be inaccessible. Some people find the beds in accessible rooms are too high for transfers. Due to a trend in using thicker box springs and mattresses, bed heights increased over the past decade, posing significant obstacles for wheelchair users.

Although the average wheelchair seat is 19 inches high, beds in hotel rooms may be 25-30 inches high.

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ADA Standards for Accessible Design contain specifications for many aspects of accessible hotel rooms, such as doorways and show-

ers, but federal standards do not specify minimum and maximum hotel bed heights. In response, the DOJ is expected to release an Advanced Notice of Proposed Rulemaking in the fall regarding non-fixed equipment and furniture, which would include maximum bed heights in accessible rooms.

File A Complaint

If you've encountered disability-related airport issues, such as inaccessible airport shuttles, trains or hotel shuttles, file a complaint with the Federal Aviation Administration on its website:

[faa.gov/about/office_org/headquarters_offices/acr/com_civ_support/filing_complaint](https://www.faa.gov/about/office_org/headquarters_offices/acr/com_civ_support/filing_complaint).

If you were not provided accessible public transportation services, file a complaint with the Federal Transit Administration at [transit.dot.gov/regulations-and-guidance/civil-rights-ada/file-complaint-fta](https://www.transit.dot.gov/regulations-and-guidance/civil-rights-ada/file-complaint-fta).

If a rental car, taxi or rideshare company didn't provide proper accommodations or you encountered problems at your hotel, file a complaint on the Department of Justice's website at beta.ada.gov/file-a-complaint.

Danica Gonzalves is PVA's advocacy attorney and can be reached at danicag@pva.org. ■

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COURTESY OF BROOKS REHABILITATION



A study participant, left, learns how to use the MagTrack controller to drive a power wheelchair.

Teams of physicians, clinical therapists and engineers at Brooks Rehabilitation, headquartered in Jacksonville, Fla., in collaboration with the Georgia Institute of Technology (Georgia Tech) School of Electrical and Computer Engineering in Atlanta, recently completed their study on the MagTrack technology, a cutting-edge assistive technology that enables power wheelchair users to control their smartphone, computer or other devices and drive their power wheelchairs using an alternative, multimodal controller.

In addition, the assistive device is designed to be wearable, wireless and adaptable to the user's specific condition and range of motion.

"MagTrack is an innovative assistive technology aimed for those living with physical paralysis to have access to more complex human-machine interactions, which will facilitate the control of more devices in their everyday life that they cannot easily use otherwise," says Nor-dine Sebkhi, co-creator of MagTrack, technical lead in the development of this assistive technology and post-doctoral researcher at the Georgia Tech Inan Research Lab in the School of Electrical and Computer Engineering. "The development of our wearable alternative controller eliminates the need for having multiple assistive technologies, replacing them with a single multimodal and integrated system."

The Study

Feedback from the Brooks clinical team

and its patients has allowed Georgia Tech engineers to transform their early research prototype into a user-ready version that was tested by more than 17 power wheelchair users living with tetraplegia, a form of paralysis caused by spinal-cord injury (SCI) that affects the arms, hands, trunk, legs and pelvic organs.

The collaboration between the Brooks and Georgia Tech teams has created a path to a first-of-its-kind, innovative application for individuals living with disabilities.

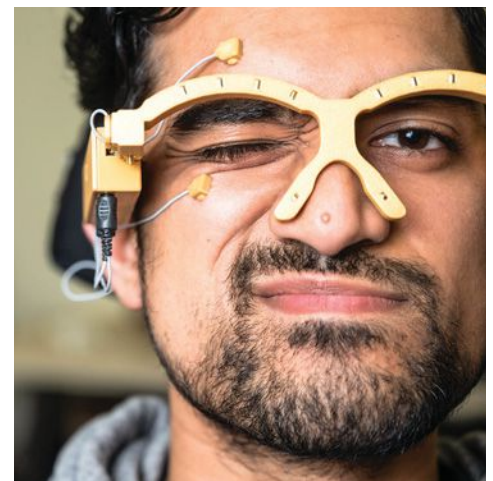
The teams brought together multidisciplinary expertise in advanced science, technology and clinical rehabilitation.

"We met with the Georgia Tech team years ago, when we first heard of the research breakthroughs they were achieving for wheelchair users," says Geneva Tonuzi, medical director of the SCI program, the SCI and related disorders day treatment program and Cyberdyne Hybrid Assistive Limb therapy at Brooks Rehabilitation. "Brooks is constantly looking for technology that is useful for our patient population living with spinal-cord injuries and mobility impairments. To see where the MagTrack project has advanced even just since the early stages of this study is incredible."

The MagTrack study was published in April in *IEEE Transactions on Biomedical Engineering*.

From the beginning, the MagTrack studies have tested the performance of the Head-Tongue Controller (HTC), an earlier version of the MagTrack technology, on its ability to perform complex human-machine interactions that will enhance users' quality of life.

The MagTrack's HTC allows the user to perform a variety of complex tasks in a single controller through



MagTrack's tracers can stick to a person's face for many hours thanks to a transparent bio-compatible adhesive.

ALISON CARTER/GEORGIA INSTITUTE OF TECHNOLOGY



Pictured, from left, are researchers Omer Inan, director of the Georgia Institute of Technology Inan Research Lab, Linda J. and Mark C. Smith chair in bioscience and bioengineering, associate professor in the School of Electrical and Computer Engineering and adjunct associate professor in the Wallace H. Coulter Department of Biomedical Engineering; Nordine Sebkhi, co-inventor of MagTrack and postdoctoral researcher at the Inan Research Lab; and Arpan Bhavsar, co-inventor of MagTrack and research engineer at the Inan Research Lab.

tongue and head movements, which are detected by eyewear and a tiny tracer that is temporarily glued onto the tongue using Glustitch's PeryAcryl bio-compatible adhesive.

Target-specific commands are generated from these motions using advanced data processing and machine learning models.

This combination of input modalities allows the user to perform a variety of daily functions with customizable control, from performing complex computer tasks (e.g., mouse navigation, scrolling, drag-and-drop) to completing advanced driving maneuvers when connected to a power wheelchair.

In the latest study, researchers connected the MagTrack technology to a single power wheelchair donated by Quantum Rehab and recruited 17 patient volunteers from Brooks Rehabilitation to test the device's functionality and usability by completing sets of both simple and advanced driving tasks.

Results showed that new MagTrack users can complete these tasks as fast, and sometimes even faster, with the MagTrack's HTC rather than their personal, alternative controller.

Since the study session lasted less than three hours — and in a power wheelchair that wasn't participants' own — it is anticipated that they would be more proficient, and thus perform better, with MagTrack, if they were given more time to familiarize themselves with its multimodal capabilities and using their own power wheelchair.

"Working with all of the participants has been very rewarding," says Jesse Milliken, a speech-language pathologist in the SCI program at Brooks Rehabilitation Hospital. "Each patient who came in was someone who has been directly affected by a spinal-cord injury and who can truly benefit from this technology. It was amazing to see how their faces lit up when they saw they were able to control their wheelchair with such ease and comfort. They all said they can see this improving their day-to-day lives if it were available to them. It's been such an honor to be a part of this process and see the work and thought process behind such advanced technology."

Patients from the Brooks SCI program who have participated in Phase 3 of the study call the advancement "exciting" and a "great system that can be used for so many things." After experiencing the technology themselves, they believe it will "touch the lives of those who are able to use it."

Improving Lives

To date, the head array and sip-and-puff are the most common alternative controllers recommended by physical therapists to individuals living with tetraplegia, while specialized switches and joystick technology are available for those with mobility in their upper extremities. These technologies were developed many decades ago for the basic need of controlling a power wheelchair.

Since then, a lack of innovation in this field has hindered these assistive technologies from adapting to today's technology. Furthermore, they are affixed to the wheelchair, which becomes inaccessible once the user is transferred to a bed, couch or any location away from the wheelchair.

Therefore, there is a growing need for this population to have access to new, alternative controllers that will enable them to be active members of an interconnected digital world.

"The trajectory of the MagTrack study shows an unprecedented possibility for the advancement of independent function, as well as mobility for electric wheelchair users," says Georgia Tech's Omer Inan, director of the Inan Research Lab, Linda J. and Mark C. Smith chair in bioscience and bioengineering, associate professor in the School of Electrical and Computer Engineering and adjunct associate professor in the Wallace H. Coulter Department of Biomedical Engineering. "Our team and partners are energized and motivated by the recent patient trials to continue to push this technology and its capabilities as far as possible. This technology can significantly improve people's lives. We will continue to work to see these advances in assistive technology come to life."

As a result of these studies, MagTrack has been refined to offer a fully integrated, all-in-one experience so that a user can seamlessly switch between driving his or her wheelchair

and controlling connected devices in his or her surroundings (e.g., smartphone, computer, automated door opener, smart TV). The system can be used anywhere since it is wearable, and its built-in wireless connectivity facilitates portability.

The Georgia Tech team is already working on a new version of MagTrack that is not only more inconspicuous, but also includes detection of facial gestures that significantly augments its control capabilities.

Thanks to a grant from the Georgia Research Alliance, this new version of MagTrack will be tested in a focus group at the Shepherd Center in Atlanta and in simulated testing in a home-like environment.

In the coming year, the team plans to make MagTrack available to early adopters for at-home validation testing to further improve the technology before pursuing commercialization.

This successful study is only a start since, at its core, MagTrack is a new type of body motion tracking. The Georgia Tech team is working on various MagTrack designs to be used as a wearable articulograph (to measure movements of the lips, teeth and parts of the tongue during speech) for motor speech disorders, as a hand-and-joint tracking system



The wireless MagTrack system can be easily calibrated.

for physical rehabilitation and even as a finger tracking for virtual/augmented reality applications.

The MagTrack team will be partnering with the Global Center for Medical Innovation in Atlanta to assist in regulatory strategy and project planning to transition the technology from the lab to the market.

For more information, visit magtrack.ece.gatech.edu. ■

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A WHEEL TRAVEL SOURCE

by Brittany Martin



Becoming
rent **ABLE**

With a TV show, website database, certification program and more, Becoming RentABLE is making vacation rentals more accessible for everyone.

Finding appropriate

accommodations for a family vacation is often difficult and sometimes nearly impossible for people with mobility impairments and other disabilities. But Lorraine Woodward is hoping to change that with her company, Becoming RentABLE.

The 60-year-old Raleigh, N.C., resident, who was diagnosed with muscular dystrophy at age 2 and uses an electric wheelchair, recognized the need for accessible short-term rentals and founded the company over a year ago. Originally, she intended for it to become a resource for people seeking accessible short-term rentals and those who want to build or renovate a short-term rental property to make it accessible. But it's turned into so much more.

Part of her plan to spread awareness and help educate others involves building a database of accessible vacation rentals, launching a national television show and creating a certification program.



COURTESY OF LORRAINE WOODWARD

Lorraine Woodward is pictured with a donated beach wheelchair at her Carolina Beach, N.C., vacation rental.





Lorraine Woodward, foreground, and her two sons, Nathan and Alexander, have muscular dystrophy and have often found it difficult to go on family vacations because of all the equipment they need.



The Woodward family's Carolina Beach, N.C., accessible vacation rental is listed on Airbnb and VRBO.

As the mother of two sons, 26-year-old Nathan and 24-year-old Alexander, who also have muscular dystrophy, Woodward understands the frustration that comes with traveling when you have a mobility impairment. That's why after her sons graduated from high school, she and her husband, Robert, decided to build a beach retreat at Carolina Beach, N.C., so the whole family would have an accessible place to vacation together.

Woodward says they listed their rental unit on Airbnb and VRBO to bring in some

additional revenue and help other families like theirs enjoy a beach vacation. But last year, she decided she wanted to do something more.

"Families are traveling from all over the country, even from Canada, and I ask each and every one why, and it's like, 'Because there's nothing else like there [the beach house],'" she says. "At the beginning, before I started this venture, I'm like, 'No, no, no, no, no, there has to be.' And it's like, 'No, Lorraine, there's not.' And then I started doing the research, going, 'Wow.' It's not [just] that there's not a lot of them

The Carolina Beach, N.C., vacation rental includes a wet room.



around, which is true. They're also hard to find. It's very laborious to go through some of these large platforms when their filters are limited."

Creating A TV Show

Taking what she learned from her personal experiences, she thought of creating a TV show and recruited her friend and producer Valerie Venable to help figure out a name, format and best path to launch it.

"I felt like if we could get more information out about what people need if they're to enjoy a vacation and how to do it, we might have more [available properties]," Woodward says.

They created a short promotional video to pitch the idea to Hulu, Netflix, Discovery Channel, Magnolia Network and HGTV. The show takes viewers through the construction process for accessible short-term rentals in vacation destinations or college and university environments. It'll showcase the property and its owners, as well as a family that uses the rental and how it made a difference for them.

But before attempting to pitch the show to producers, Woodward worked with Harvard University adjunct professor Kelsey Viscount to develop a survey to validate her concept, build credibility and establish her company's area of expertise. Because accessibility means different things to different people, the survey identified a variety of areas for people to address what their needs are while traveling. Woodward then reached out to organizations, including Easterseals, United Cerebral Palsy



The Little Yellow House in Conway, Ark., will be what Lorraine Woodward calls a "gold-standard property" in terms of accessibility for all disabilities.

and the Muscular Dystrophy Association, to distribute the survey to a large group.

The next step was finding properties to feature on the show.

"As we're looking for these properties, we realized through the survey that, you know what, so many times when you think of accessibility and you think of accessibility in a short-term rental, you associate it with wheelchair access," Woodward says. "But wait a minute, there are people who still have special needs that might use a walker. They

Below left, The Little Yellow House's back entrance will have a ramp. Below right, The Little Yellow House bathroom gets a makeover.





MORGAN FLANAGAN



MORGAN FLANAGAN

The Little Yellow House will feature a fully accessible kitchen.

might have an intellectual disability. They might have autism, vision, hearing [impairments]. Why are we limiting it to just wheelchairs? So, in the beginning of our process late last spring, early summer, we took a step back and said, 'Wait a minute. We want to look at accessibility in broader terms.' We really want to change the way that we look at accessible short-term rentals and not just include the mobility of a wheelchair."

With that in mind, she and Robert bought a bungalow they've dubbed The Little Yellow House in Conway, Ark., known as the City of Colleges. It's also home to Woodward's mother, Marianne Berry, who Woodward had only visited twice in the last 35 years due to lack of accessible places to stay.

Intending to make the house what Woodward calls a "gold-standard property," they had it gutted and are making it accessible for wheelchairs, walkers and people with autism, intellectual or developmental disabilities (IDD) and vision or hearing impairments. While it will be a working short-term

rental, for Woodward, its primary purpose will be to educate individuals, organizations and the short-term rental community about the importance and value of creating more accessible short-term rentals. The Little Yellow House was set to be completed in late April.

Other properties that will be featured on the show will be a condo near North Carolina State University in Raleigh, N.C., which should be completed in September, and a home in Knoxville, Tenn., which is about a year from completion. So far, they have taped the first episode, focusing on their Carolina Beach property, and video and still photography are being used to document the developments of the other three properties.

"We're at a stopping point right now because once we do get somebody to pick it up, they may have their own ideas of, 'No, we want to use this person as a host. We want to do this,' ... from working with other producers in the industry, we've done what needs to be done until we go pitch," Woodward says.

This property in Knoxville, Tenn., will be part of Becoming RentABLE's potential television series.



COURTESY OF LORRAINE WOODWARD

A condo unit being built near North Carolina State University in Raleigh, N.C., is an accessible property that will be featured on Becoming RentABLE's future television series.

Finding Properties

Meanwhile, Woodward is working to make it easier for people to find accessible properties.

She's assembled a team of more than 15 volunteers to scour the internet to validate and curate accessible properties for her website, becomingrentable.com, that fall within five disability focus areas: wheelchair accessible, walker-friendly, autism/intellectual or developmental disabilities (IDD), vision and hearing. So far, they've identified more than 600 properties in the continental U.S. that fulfill specific criteria, and those properties are searchable with 33 filters on the website. The site also allows rental owners to submit their property for review under a feature called "List My Property."

One of Woodward's volunteers is Tina Crawford-Bright, who wanted to help Woodward after vacationing for a week with her family at the Carolina Beach rental last July. She sustained a level C5 spinal-cord injury in a 1999 car accident and lives in Lindsie, W.V., and has been helping research accessible properties online to add to Becoming RentABLE's inventory map. Crawford-Bright also was inspired to do a fundraiser last year for a beach wheelchair that now stays at the Carolina Beach property for other renters to use at the beach. She sees the importance of what Woodward is trying to accomplish, and she hopes to help others who are facing the same accessibility problems.

"Just for somebody to be able to go to a home and stay there and not have to worry about where's the shower chair? OK, this house is full of carpet. Carpet, for me, does not work," Crawford-Bright says. "Being able to be more independent, that's part of it for me, be as independent as I can. That's Lorraine, too. She's very headstrong and independent. I think that's why we came together."

To improve awareness even further, Becoming RentABLE recently launched a YouTube channel (youtube.com/channel/UCPY0kd6_WVPFF2n5n0ZSCIA/featured) and will be adding educational materials and videos to guide property managers during their construction phases. In addition, Woodward



COURTESY OF GLENN WOOD AGENCY

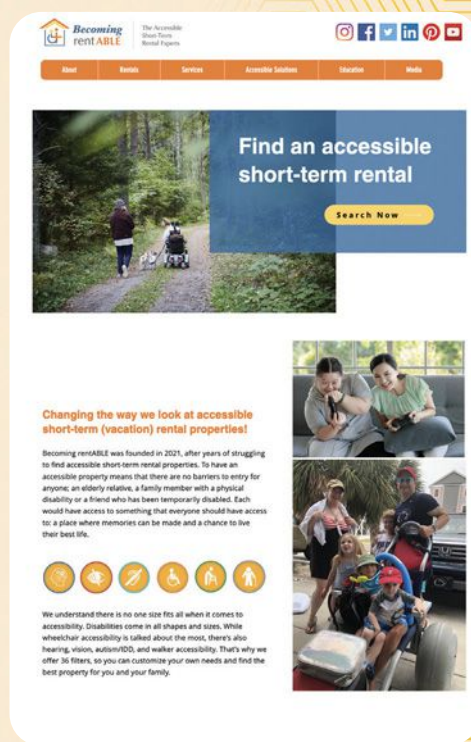
and her team created a certification program to validate and identify properties as wheelchair accessible, walker-friendly or autism/IDD-friendly using a medallion or icon on the property listings.

"Currently, you don't know when you're going through 7,000 properties looking for something that's going to meet your family's needs. You just have to keep looking and looking," Woodward says. "So, we're hoping it will give that visual ID of recognition that, A, it is what it says it is, but it will [also] make the search easier for people is what our hope is."

Woodward just wants to make a difference and help people travel — and she wants to travel herself.

"If anyone is building, anybody has or wants to have an accessible short-term rental, we are their source," Woodward says. "We would like to post their property. We would like to give them information about what it takes to be a wheelchair/walker friendly, autism-friendly type property. We want to know people who would like to be a part of our show."

For more information, visit becomingrentable.com. ■



BECOMINGRENTABLE.COM

FLIGHT PLAN



From advocacy to surveys to websites, PVA is continuing its fight to improve air travel for all passengers with disabilities.

by Heather
Ansley, Esq., MSW

The summer travel sea-son is just heating up, and the ease of novel coronavirus (COVID-19) restrictions means more people are flying. But not everyone has the same experience when hitting the “friendly skies.”

Broken wheelchairs, passengers being dropped during transfers and plenty of other problems persist for people with spinal-cord injury and disease and others with disabilities decades after the passage of the Air Carrier Access Act (ACAA).

Paralyzed Veterans of America (PVA) has been working to address issues like those and

improve everyone’s access to air travel for more than 40 years.

In the mid-1980s, PVA filed a lawsuit that went to the United States Supreme Court seeking access to air travel under Section 504 of the Rehabilitation Act of 1973, in light of the federal investment in the air travel system in the U.S.

Although the Supreme Court didn’t find in PVA’s favor, the decision resulted in the late-Sen. Bob Dole of Kansas introducing the ACAA. The ACAA was signed into law by then-U.S. President Ronald Reagan in 1986. When the Americans with Disabilities Act



ILLUSTRATION BY KERRY RANDOLPH © GETTY IMAGES/JAG_CZ

was passed four years later, it explicitly didn't cover air travel.

The ACAA prohibits disability-based discrimination in air travel, and although it has improved the consistency of the air travel experience, it hasn't led to widespread improvements despite 35 years of opportunity.

In recent years, PVA has advocated for changes that would provide a safe and dignified experience for not only wheelchair users, but for all people with disabilities.

Survey Results

To learn more about the current experience of air passengers with disabilities, PVA and 11 other veterans and disability rights organizations designed and promoted an informal online survey last fall.

The survey's goal was to gather information that would help improve the ACAA and make air travel better for all people with disabilities. Starting last October and lasting about eight weeks, PVA collected travelers' responses.

Nearly 1,300 individuals responded to the survey, which covered a wide variety of accommodations for passengers with disabilities. Not all questions were applicable to all travelers due to differences in needed accommodations.

The survey provided helpful information and supported the anecdotal reports received from PVA members. Over half of the survey respondents had flown in the past 12–24 months, and the vast majority noted that they typically fly once or twice year. Notably, a little over 9% indicated that they don't travel by air.



Air travel for people with disabilities comes with issues such as lack of physical access to lavatories and improper assistance with boarding and deplaning.

There may be a variety of reasons why anyone chooses not to fly, but the consensus from passengers who use wheelchairs was that air travel is too difficult and a risk to their health because of lack of physical access on airplanes and improper assistance in boarding and deplaning.

In order to understand whether certain barriers had resulted in passengers with disabilities avoiding air travel, PVA asked them to select from a list of possible concerns that resulted in them avoiding air travel. The more than 1,000 respondents for this question selected the following concerns:

- 74% chose potential damage to their wheelchair
- 63% selected not being able to use a bathroom on the aircraft
- 54% said personal safety in transferring from a wheelchair to an aisle chair and into an aircraft seat
- 36% picked issues related to their need for personal care, a personal care aide and/or traveling companion
- 12% selected issues related to their need for effective communication
- 9% said issues related to their service animal

With regard to concerns about bathroom access, nearly 56% of respondents to whom the question was applicable said that not having access to a lavatory was by itself reason enough not to fly unless absolutely necessary.

Smart Business

Although PVA often hears from airlines that more advance notice would improve their ability to serve passengers with disabilities, 83% of respondents indicated that they always provide the airline with information about any needed accommodations when they purchase their ticket.

Some respondents noted, however, that it can be difficult to specify what you need when purchasing tickets online. Some of those who call the airline to discuss accommodations reported encountering long waits. Some also noted that despite making their requests known, they didn't receive needed accommodations.

It's important to point out that passengers with disabilities are customers and are an important revenue base. Over three-fourths of all respondents said they would fly at least a few times a year if the experience were improved. Fifteen percent said they would fly monthly. Thus, addressing concerns with air travel is not only required for equity — it's also a smart business decision.

The survey included several questions specific to those who use wheelchairs. Over half of respondents reported needing an aisle chair to board and deplane. The most common answers from those who use aisle chairs were that they're difficult or unsafe to use, they're in disrepair and they're not readily available for use when needed.

Respondents also commonly reported that they felt personnel weren't properly trained to assist them in using an aisle chair and that they have felt unsafe using one. In addition, 16% said they had been dropped and 23% said they had been injured while using an aisle chair.

The survey also sought information about wheelchair damage. When a wheelchair is lost, damaged or delayed, it's a significant and serious problem for the individual who relies on that device for his or her mobility, independence and well-being. It can mean the end of the trip, as the individual is forced to forgo the entire reason for travel while he or she waits on the repair of his or her wheelchair. It can also mean months of using a loaned chair that doesn't fully meet his or her needs.

Of those who travel by air with a wheelchair or scooter, almost 60% reported their device having been damaged. Almost 56% had experienced delays in its return. Twenty-eight percent reported losing a device's accessory, and 17% reported having a wheelchair or scooter lost.

Moving Forward

Until such time as passengers are able to board using their own wheelchairs, more must be done to improve the safety of boarding/deplaning devices.

This past February, PVA petitioned the Department of Transportation (DOT) to initiate rulemaking authority that would implement improved standards and requirements for boarding and deplaning airline passengers with mobility impairments.

During a March DOT public meeting on issues that impact wheelchair users in air



COURTESY OF PARALYZED VETERANS OF AMERICA



COURTESY OF PARALYZED VETERANS OF AMERICA

travel, PVA presented the survey data and asked the DOT to act on its petition. PVA believes the DOT should mandate that airlines assign specific airline personnel who are highly trained in how to board and deplane passengers with significant mobility disabilities.

Personnel who physically lift wheelchair users must have higher levels of training than those who are providing other types of assistance. This assistance must be "hands on," and individuals should receive an annual certification of their skills, including their ability to follow directions from passengers about how to effectively and safely assist them.

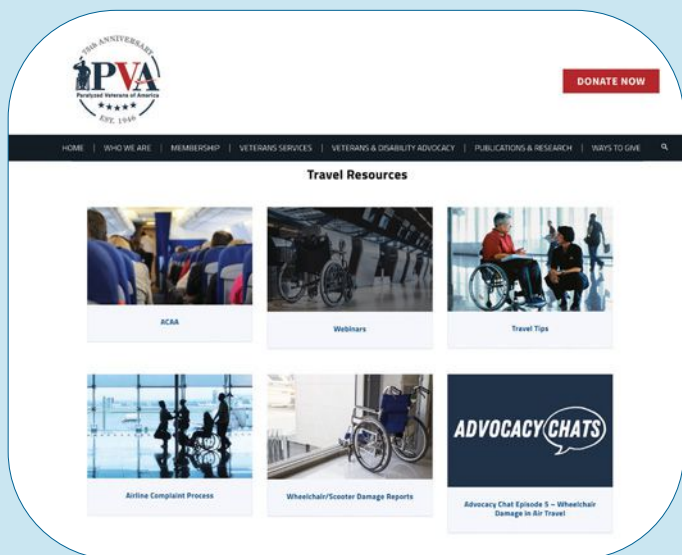
In an informal survey of nearly 1,300 respondents, 83% indicated that they always provide airlines with information about needed accommodations when purchasing a ticket.

These personnel must also be provided with properly maintained equipment, and that equipment must meet standards that address passengers', assistants' and airlines' needs.

With regard to assistive device stowage, PVA stated during the March meeting that aircraft cargo holds must be redesigned to accommodate wheelchairs and scooters, and ramp personnel must be provided with the proper equipment to safely load mobility devices.

In addition, the DOT must establish a timeline for airlines to adhere to when replacing a wheelchair or other assistive device or providing compensation for the damage of such a device, as well as requiring air carriers to provide adequate interim accommodations. Finally, the DOT should clarify regulations that require airlines to return all wheelchairs and other assistive devices in the condition in which they were received.

Aside from action the DOT should take, PVA also urged Congress to pass the Air



Paralyzed Veterans of America offers travel resources at pva.org/airtravel.

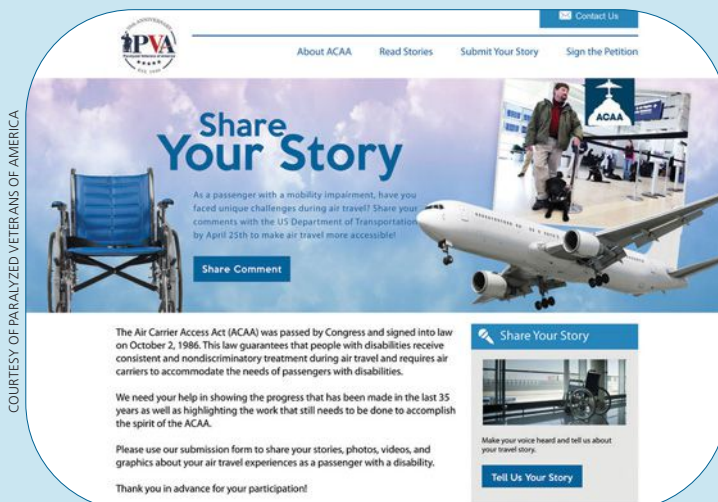
Carrier Access Amendments Act (HR 1696/S 642). This legislation would establish a private right of action and increase administrative enforcement of the law. It would also require creation of a set of physical access standards that new airplanes have to meet, as well as require removal of access barriers on existing airplanes, if readily achievable. Passage of this legislation would set air travel on a path to at last meet the accessibility needs of passengers with disabilities.

Finally, PVA relaunched its air travel webpage last fall to update resources for travelers with disabilities. PVA also added an animated video that describes wheelchair users' experiences in navigating air travel and highlights PVA members' and employees' stories to illustrate common problems.

In addition, PVA used last October's 35th anniversary of the ACAA to rebrand the air travel story portal, air-access.org.

To keep up with PVA's efforts to improve air travel, visit pva.org/airtravel.

Heather Ansley, Esq., MSW, is PVA's associate executive director of government relations in Washington, D.C. ■



To help Paralyzed Veterans of America improve the air travel experience, share your story at air-access.org.



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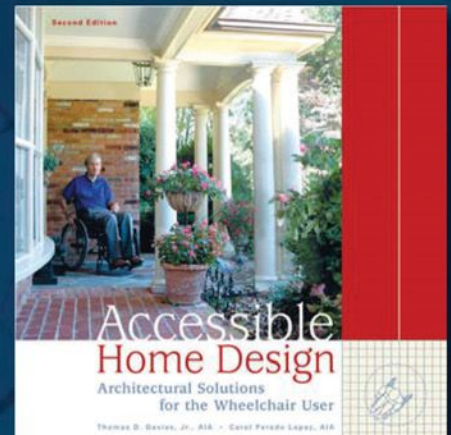
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A STIMULATING



ILLUSTRATION BY KERRY RANDOLPH/PHOTOS THIS SPREAD COURTESY OF ONWARD

Researchers are working to improve quality of life and restore locomotion in people with SCI using purpose-built electrical stimulation devices.

by Brittany Martin

The news made interna-tional headlines last February when three research study participants in Switzerland with complete spinal-cord injuries (SCI) who were implanted with specialized electrical stimulation devices could stand, walk with the help of a walker, cycle and swim independently in a community setting with just five months of training.

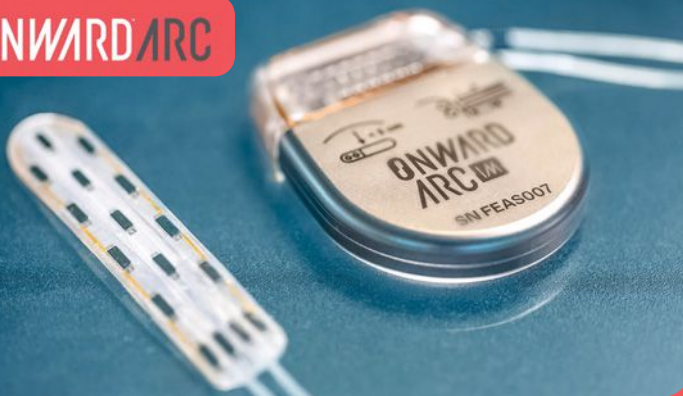
While the results showed promise in helping restore locomotion for people with complete SCI, that proof-of-concept study published in *Nature Medicine* is just the beginning of what the team aims to accomplish.

Taking what they learned from animal models (rats and non-human primates) and a 2018 clinical feasibility study called Stimulation Movement Overground (STIMO) in humans with incomplete paraplegia using epidural electrical stimulators designed for pain management, lead researchers Grégoire Courtine, PhD, and Jocelyne Bloch, MD, utilized purpose-built, closed-loop stimulation devices to help participants with clinically complete thoracic SCI regain movement in the STIMO Bridge study.

But the same technology, created by medical technology company ONWARD, also has

WALK

ONWARD ARC



The ARC-IM is the implantable version of a spinal-cord stimulator being tested and developed for people with spinal-cord injuries.



the potential to improve more immediate quality-of-life issues for people with SCI, such as blood pressure and torso control and recovery of hand and arm functions.

Founded in 2014 by neuroscientists from the Swiss Federal Institute of Technology (EPFL) in Lausanne, Switzerland, ONWARD has been working with Courtine, an EPFL neuroscience and neurotechnology professor, and Bloch, a neurosurgery professor at Lausanne University Hospital, to test and develop both its transcutaneous and implantable spinal-cord stimulators.

ONWARD CEO Dave Marver says Courtine's and Bloch's NeuroRestore group conducts basic science and preclinical research and demonstrates feasibility in a small number of human subjects, then ONWARD becomes the commercialization engine to obtain Food and Drug Administration (FDA) approval and puts the support organization in place for clinics that adopt the technology. The



goal, he says, is for ONWARD to offer a whole menu of choices that would enable somebody with SCI to address whatever's most important to him or her, whether it's standing, walking, bladder and bowel control, sexual function, hand and arm mobility, autonomic dysreflexia regulation and more.

From left, Grégoire Courtine, Jocelyne Bloch, MD, and Dave Marver are leading the testing and development of both transcutaneous and implantable spinal-cord stimulators.



The ARC-EX includes two sticker-type leads that stimulate the spinal-cord to allow a person to move his or her arms and hands.

“We have a different vision now, which is that empowered by movement, people with spinal-cord injury will enjoy life in every way that matters to them, which is a recognition that not everyone with SCI prioritizes the ability to walk again,” Marver says. “Some just want to stand. Most want use of their hands and arms. Others want to go to the bathroom without having to catheterize eight or 10 times a day. So, there’s just a number of other challenges that can really improve



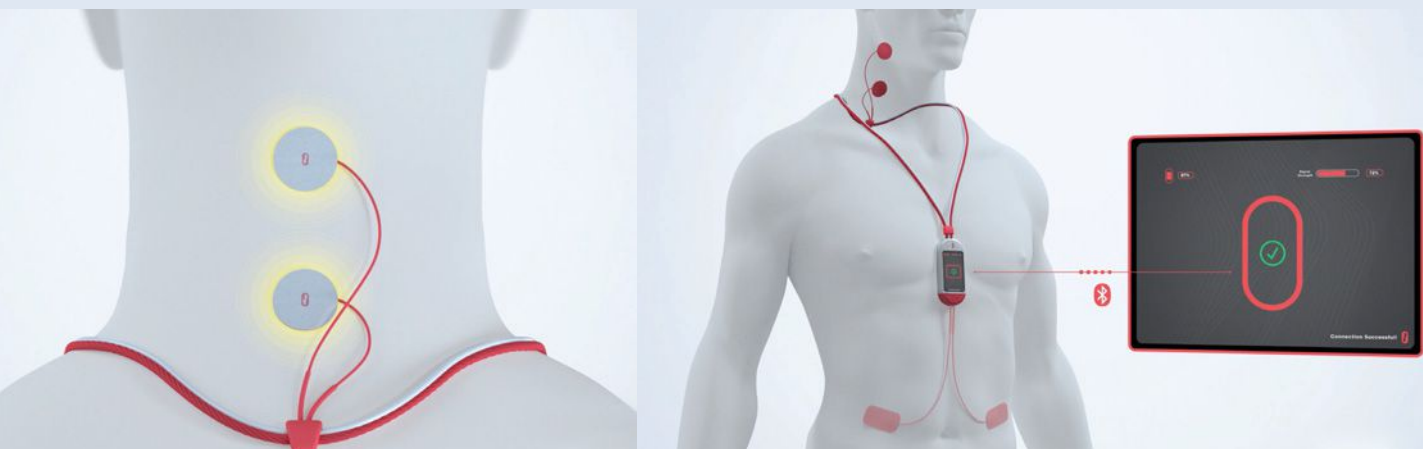
ALL PHOTOS THIS PAGE COURTESY OF ONWARD

The noninvasive ARC-EX spinal-cord stimulator is modulated through a handheld controller.

activities of daily life, and we want to help in all of those ways.”

Targeted Therapies

The first therapy device the team plans to introduce to the U.S. market in late 2023, pending FDA approval, is for improvement in hand and arm function and strength. ONWARD’s ARC-EX transcutaneous system is being studied in a trial called Up-LIFT at 14 SCI centers worldwide, including the Department of Veterans Affairs



The ARC-EX transcutaneous system is undergoing clinical trials in 14 spinal-cord injury centers worldwide and could be available for U.S. patients by late 2023.



Michel Roccati, who sustained a level T6 spinal-cord injury in 2017, walks with a support harness following implantation with the ARC-IM spinal-cord stimulator.

Bronx Healthcare System in New York, Craig Hospital in Denver, Shepherd Center in Atlanta and at the University of Washington.

The noninvasive external device connects to sticker-type leads that are placed on the skin to stimulate the spinal-cord area that's responsible for a given movement. To stimulate the hands and arms, two leads are placed on the patient's neck, and stimulation is modulated through a handheld controller that's connected to A/C power.

Marver says further FDA approval would allow its use in the home, so a clinician could write a prescription for a patient to use the device to either reinforce movement gains from clinic use or to help make further gains over time.

Next, Marver says they'll turn their attention to larger clinical studies for the implantable version, ARC-IM, to demonstrate safety and effectiveness in blood pressure and torso control. The system utilizes ONWARD's new purpose-built leads to deliver stimulation, whereas previous research studies have used repurposed devices designed for pain management.

The implant includes a pacemaker-like device that's placed in the patient's abdomen and connects to a flexible lead that's inserted between the vertebrae in the epidural space below the injury level, near the part of the spinal cord that's responsible for the targeted functions.

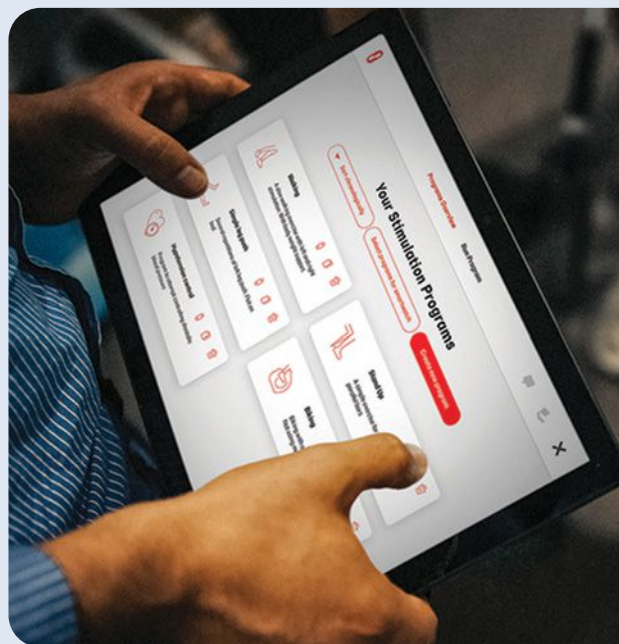
Marver says ONWARD's lead is a bit larger than conventional leads, and its 16 electrodes are optimized to stimulate the dorsal nerve roots that convey information from the muscles to the central nervous system. The larger leads make trunk control possible, but also standing and walking, which was demonstrated in the

three STIMO Bridge study participants with complete SCI and will be addressed in a later series of larger clinical trials.

"Previously, spinal-cord stimulation had been done with tonic, or steady, stimulation through a general region," Marver says. "This stimulation was done in a very precise way through individual electrodes on the lead to stimulate the muscles in the exact pattern that's required for gait or for walking."

It's that targeted stimulation with a specific tempo and pattern that allowed STIMO Bridge trial participants like 30-year-old Michel Roccati of Montaldo Torinese, Italy, to walk, pedal a bicycle and swim using preprogrammed activity modes on a tablet computer.

The ARC-IM includes a tablet computer software interface that communicates wirelessly with the implant and allows rapid fine-tuning.



Roccati says he never gave up the hope of one day walking again after sustaining a level T6 complete SCI in a 2017 motorcycle accident.

"I love fitness. Now I have a stimulation program for every equipment in my gym," he says in an email. "For example, I have a program for the rowing machine, one for the cyclette [exercise bike] and many others. I also have a program to climb stairs alone. This is very important because now those who accompany me no longer have to lift me up with the help of another person. With the 'Standing' program, I can have standing appointments with my clients and stay at the same height level. Stimulation has definitely changed my life."

Empowering Recovery

As much potential as ARC-IM appears to have, it does require surgery and months of rehabilitation.

In a Feb. 17 webinar hosted by the Christopher & Dana Reeve Foundation, Bloch describes the procedure for implanting the stimulator as the same procedure that's been used for years to treat neuropathic pain, although in this surgery, she says precise placement is more important.

The three STIMO Bridge participants were enrolled between July 2019 and August 2020, were at least a year post-injury and had

David Mzee, who was paralyzed in a gymnastics accident in 2010, was part of the 2018 Stimulation Movement Overground clinical feasibility studies.



COURTESY OF ONWARD



Michel Roccati practices walking with a walker outside a laboratory in Switzerland.

at least 6 centimeters of healthy spinal cord below their injury. Marver says participants were asked to train for three weeks prior to the device implantation to acquaint them with the equipment and to exclude the possibility that post-implant physical training alone could positively impact the improvements recorded while training with the stimulator.

Courtine and Bloch say patients could stand and take a few body weight-supported steps with the stimulation turned on the day after surgery.

"The first time I turned on the stimulation and it allowed me to stand up, it was really exciting," Roccati says. "At that moment, it was difficult to find the right words to describe my state of mind. I think I was silent for 10 minutes."

Patients also reported improvements in sexual function, bowel activity and blood pressure stability, but there was no consistent recording of that data because it wasn't part of the original protocol.

Though the post-implantation training time varied, it took several months of training for at least one to two hours per day for patients to walk outside the lab and five months before they could swim and cycle because they had to regain muscle mass and coordination.

"I thought, 'I've done it,' and, 'The break is over. Now, I will walk every day,'" Roccati says.

Roccati trained from 9 a.m. to 6 p.m. daily during his rehabilitation in Lausanne because he wanted great results, so he stayed disciplined and focused. He now uses the stimulator about two hours a day, which he says is the best part of his day.

"Patients are training every day, four times per week for many weeks to see results," Courtine says. "So, it's not a magic bullet. Clearly, you need to be ready to commit. So, the key is for us to empower people to improve their recovery, but they need to do it."

Courtine says an important development was the tablet computer software interface, which communicates wirelessly with the implant and can be rapidly tuned by a therapist. He says the stimulator version that will eventually be available in clinics could be controlled by voice activation with a smart-watch or smartphone.

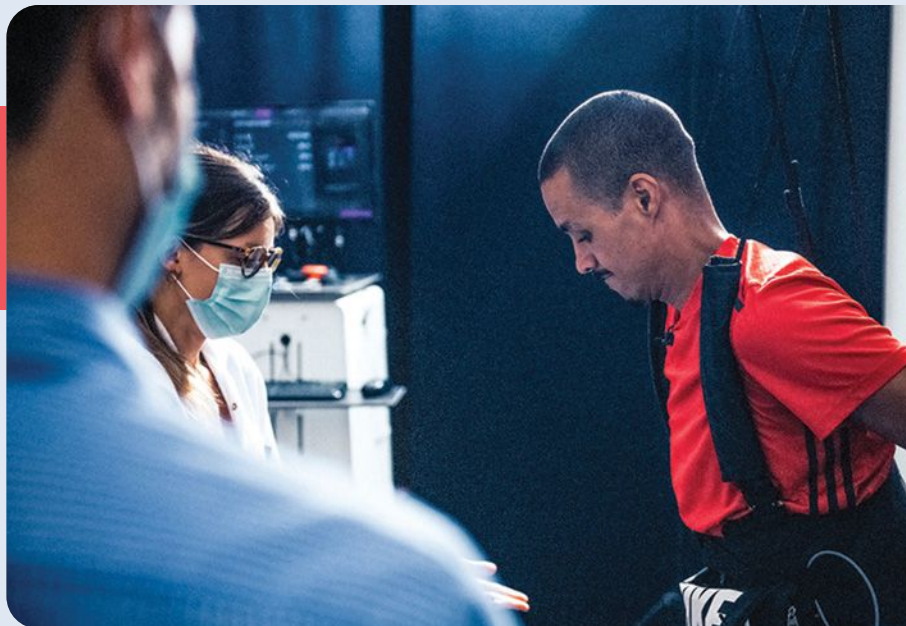
"We are not going to cure spinal-cord injury, but hope with this technology we can really improve recovery and empower people to improve their recovery and improve neurological function with this precise stimulation, which will be very easy to use because of a connected watch," Courtine says. "You can talk to your watch to trigger the stimulation, etcetera. The idea is to really be able to integrate the technology with daily life."

Marver says the final FDA-approved device will be wirelessly rechargeable through the skin. The battery will last between five and 10 years, and he says the procedure to change it is commonly done for pacemakers, defibrillators and other neuromodulation devices. The electrodes themselves are lifelong and would never need to be changed.

"In a way, it's a good thing because then the person can benefit from the next-generation technology, as well," Marver says. "The duration itself, the longevity, also really depends on how frequently the device is used, how often stimulation is applied."

Further Research

While it could likely be another three to five years before ARC-IM is FDA-approved as a



COURTESY OF ONWARD

Class 3 medical device for blood pressure control and trunk stability, Marver says it's important for ONWARD to get these therapies on the market as quickly as possible so they can be further studied and the applicability can broaden.

Future long-term studies with large patient cohorts could focus specifically on the therapy's effects on deep vein thrombosis, skin breakdowns and muscle atrophy, as well as restoring sensation and changes in autonomic dysreflexia. Bloch says future studies also could include candidates with more recent injuries, as well as those with stable, non-progressive spinal-cord diseases.

In the distant future, Courtine says they hope to run a clinical trial on a brain implant that would be linked to the stimulation device, called a digital bridge or brain-spine interface, that would allow movement just by thinking about it.

For now, Marver says ONWARD intends to prioritize the therapies and technology that will make a difference in the daily lives of most people with SCI.

"There's a lot of promising research," Marver says. "This is clearly among the most promising research that's ever been done, and there's a lot going on in Lausanne that you don't even know about yet. But none of that matters if it stays on the pages of an academic or science journal. It has to reach the clinic. It has to help people in their daily lives and their homes."

For more information, visit onwd.com or neurorestore.swiss. ■

David Mzee takes body-weight supported steps during the Stimulation Movement Overground clinical feasibility studies.

around the HOUSE

Starting An Accessible Home Project

Whether you're planning a new accessible home or improvements to your existing one, there are many

strength capabilities of those with limited mobility.

Since most existing and even new home plans will need many alterations to provide accessibility, the design should be focused on accessible features that meet your specific needs.

shower, a transfer shower or bathtub best fits you.

- What do your assistive devices already enable you to do? Using more sophisticated equipment may require less adaptation of built-in components in your home. For example, if you have upper-



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considerations involved in planning and executing a successful accessible home project.

The process doesn't have to be intimidating, especially when the Paralyzed Veterans of America (PVA) Architecture Program can share its technical expertise to assist you with making the accessible design decisions that best fit your needs.

Unlike multi-family or public housing, private residences are not mandated to meet Americans with Disabilities Act (ADA) requirements. As a result, the majority of private residences don't provide adequate maneuvering space, no-step entrances and usable hardware or devices aligned with the reach and

Determine Specific Needs

An important first step is to determine the primary user's current and anticipated future requirements that must be addressed by the finished project.

Moving through an existing home or a model home to think about and record which features support your daily needs can help. Some common issues to consider include:

- Do you have limited gripping capability in your hands? If yes, then larger, easy-to-grab cabinetry pulls may be important.
- Do you bathe independently or with assistance? Your answer will help determine whether a roll-in



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Working with an architect has many benefits, including having an advocate during construction.

body mobility and your wheelchair can adjust to different heights, shelving placement may not be as important as it would be when using a standard wheelchair.

- Is the home to be used only by a person in a wheelchair or also by ambulatory family members or caregivers? If people with different capabilities will be sharing bedrooms, bathrooms and kitchens, it is important to factor this into the design. The finished product needs to function comfortably for all users.
- Do you have specialized interests or hobbies that require sophisticated design provisions? For example, do you enjoy creative endeavors like woodworking, gardening or studio art projects? These activities may call for dedicated spaces with abundant maneuvering space and



Separating the wall oven from the cooktop improves accessibility by allowing you to vertically place the oven where it best suits your needs and provides the ability to pull under the cooktop.

equipment adaptations to fit your unique needs while maintaining a safe environment.

Design & Construction

Upon establishing your general project requirements, the design process begins.

An architect should be involved in larger undertakings, such as a new custom home or additions and significant renovations to an existing home. The work involved in these projects can quickly become complex and requires professional skill. So, while architectural design involves a fee, it can be a worthwhile investment to ensure the outcome fully meets your specific needs.

An architect can also help minimize expensive misunderstandings during the construction process and can serve as the homeowner's advocate, protecting you from pressure to make

hasty or uninformed decisions. Even for standardized plans that require minor modifications to fit your needs, it can be a good idea to employ an architect on an hourly fee basis to ensure important design issues are not overlooked. Architects can also help with seamless integration of function and aesthetics into your existing home, which many times will increase your investment value.



Installing grab bars in the right locations can improve your ability to live independently.

PVA Architecture Design Assistance

PVA Architecture is ready to assist you with improving the accessibility of your new or existing home.

PVA architects use their accessible design expertise to assist all types of homeowners during the home design phase to create a more accessible and usable home by applying the accessibility principles in *Accessible Home Design: Architectural Solutions for the Wheelchair User*. This book outlines the initial steps of how to start a project by determining your specific needs and hiring an architect, designer or contractor. In addition, there are detailed design recommendations to improve all aspects of your home's accessibility. These recommendations are organized to provide you with valuable design ideas to improve your home's accessibility — from the front door to the backyard and beyond.

In addition to the book's key information, there's an even more valuable service that PVA's Architecture Department offers to anyone interested.

If you send the department your design floor plans, a PVA-licensed architect will review the drawings



Life changing science

Our Research Center of Excellence, housed at the University of Miami Miller School of Medicine, is dedicated to finding effective treatments, improving the quality of life of individuals with spinal cord injuries, and ultimately, finding a cure for paralysis.

To be considered for current and future research studies, please visit our website: themiamiproject.org to complete our intake form

or

call our offices and request a copy of the form by mail.

For more information: call 305-243-7108 or email mpinfo@med.miami.edu



PVA PUBLICATIONS FILE PHOTO



Lowering the window sill height will improve incoming daylight and exterior views.

will be specific to your design and will include many overlooked details, such as window sill height, appliance locations/functionality, door and cabinet hardware and door swings.

PVA architects are knowledgeable in accessible design beyond codes and standards because they understand the highly specialized needs of users with spinal-cord injury and disease.

No matter how large or small your project, you should remember that even the simplest change or design feature can have an enormously positive impact on your daily life.

You can start the process of PVA Architecture technical assistance review by emailing your request and floor plans to pvaarchitecture@pva.org. Design review services are provided at no cost to you.

Mark R. Thompson, AIA, is the senior associate director of architecture with the PVA Architecture Program. ■

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Creating an accessible outdoor space with activities can improve your health and well-being.

specifically for accessible features and then provide you with review comments intended to improve the design's accessibility. Comments

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Paralyzed Veterans of America (PVA) has published the book, *Accessible Home Design: Architectural Solutions for the Wheelchair User*, as a detailed resource for homeowners, architects and builders. It's available for purchase by emailing pvaarchitecture@pva.org. The cost is \$9.99 for PVA members or \$16.99 for non-members. The book is also available on amazon.com for \$16.99.

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Discrimination Legislation

In late March, Sen. Edward J. Markey (D-Mass.) and Rep. Katie Porter (D-Calif.) introduced The Disabled Jurors Nondiscrimination Act, legislation that prohibits excluding a person from federal jury service on account of a disability.

Currently, federal law prohibits excluding an indi-

vidual from jury service on account of race, color, religion, sex, national origin or economic status. The new legislation adds the word “disability” alongside those protected characteristics.



vidual from jury service on account of race, color, religion, sex, national origin or economic status. The new legislation adds the word “disability” alongside those protected characteristics.

The bill also clarifies provisions of federal law governing juror qualifications by amending the statute under which jurors are qualified to serve unless they are “unable to read, write and understand the English language with a

degree of proficiency sufficient to fill out satisfactorily the juror qualification form” or “unable to speak the English language.”

The bill clarifies that no person may be disqualified from serving on a federal jury under those provisions on account of a disability. Under the bill, it would be clear that a person who uses Braille or American Sign Language is not “unable to

read, write and understand the English language” or “unable to speak the English language.”

A copy of the legislation can be found at [markey.senate.gov/imo/media/doc/sil22489.pdf](https://www.markey.senate.gov/imo/media/doc/sil22489.pdf).

Potential Therapy Target For ALS

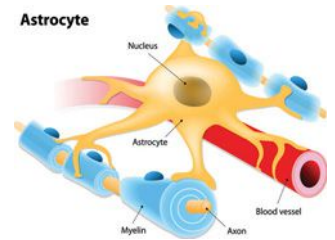
Johns Hopkins Medicine researchers in Baltimore have found a possible win-

dow of opportunity during amyotrophic lateral sclerosis (ALS) treatment to target astrocyte abnormalities — a subtype of cells in the central nervous system that provide a structure to metabolically support neurons and fine-tune neuron network signaling.

The research team believes that astrocytes are actively involved in the death of motor neurons, which are cells in the brain and spinal cord that allow people to move, speak, swallow and breathe by sending commands from the brain to the muscles that carry out these functions.

“We think this is particularly important because the astrocyte dysfunction is active after symptom onset in patients with ALS,” says Nicholas Maragakis, MD, professor of neurology at the Johns Hopkins University School of Medicine and medical director of the Johns Hopkins ALS clinical trials unit, in a Johns Hopkins Medicine release. “This finding may enable us to target abnormalities in astrocytes for ALS treatment.”

In their study, published March 21 in the *Proceedings of the National Academy of Sciences of the United States of America*, researchers analyzed brain and spinal-cord tissues from patients with ALS and observed that a particular astrocyte protein, connexin 43, acts as an open pore



that sends toxic factors to the motor neurons from the astrocytes. The pore was particularly active in patients with ALS who have a family history of the disease and those who contracted the disease in a sporadic fashion.

The research team developed stem cell lines from patients with ALS and made them into astrocytes. They found that these astrocytes induced motor neuron death through hemichannels (proteins that provide pathways for the movement of molecules among cells).

Maragakis says pharmaceuticals are being developed that could block this hemichannel. During the study, Maragakis and his team showed that tonabersat, a drug originally developed for migraine and epilepsy treatment, could block astrocyte-induced motor neuron death in human ALS stem cell lines and animal models.

This study, Maragakis says, offers increasing evidence that astrocytes play a role in the spread of ALS. Next, the team will try to establish why this hemichannel is so active in ALS astrocytes, giving them a

better understanding of how the disease progresses. Maragakis says it's equally important because it furthers his team's work to identify new drugs that can block this particular hemichannel, serving as future therapeutics for ALS.

Microbiome & ALS

Researchers at the University of Illinois-Chicago are looking at the possibility that gastroenterological changes could be an early warning sign for amyotrophic lateral sclerosis (ALS). Their research in animal models also shows a promising treatment to slow the disease's progression.

Jun Sun, PhD, professor of gastroenterology and hepatology in the University of Illinois College of Medicine, is the lead author of both a research paper and a research review that suggest a potential role of intestinal inflammation and microbiome in the development and/or the progression of ALS.

Sun says she heard about U.S. military veterans who had gastrointestinal (GI) issues while they were serving overseas and were later diagnosed with ALS. Several research studies have shown veterans have an elevated risk of developing ALS. Sun says there are still few answers as to why to those who

served in the military are at a higher risk of ALS.

ALS patients and their families had written to Sun, indicating they noticed GI symptoms before their ALS diagnosis. After reviewing published research dating back to 1967, for the review paper, A gut feeling in amyotrophic lateral sclerosis:

microbiome of mice and men, published March 11 in the journal *Frontiers in Cellular and Infection Microbiology*, Sun and her team found collective evidence of GI symptoms in ALS patients. However, there was no research on GI symptoms pre-ALS diagnosis. Because there are no clear guidelines on the early diagnosis for ALS, symptoms often get confused with other health problems, Sun says.

For their November 2021 research study, Aberrant enteric neuromuscular system and dysbiosis in amyotrophic lateral sclerosis, published in the journal *Gut Microbes*, researchers in Sun's lab studied the impact and mechanism of enteric neuron system, a mesh-like

system of neurons governing the functions of the GI tract, and the microbiome in ALS mice, which carried the mutated superoxide dismutase 1 (SOD1) gene, one of the human genes that triggers familial ALS.

Because there were challenges to study the GI symptoms and microbiome

mice that were treated with butyrate, these decreases took significantly longer to appear, according to the study. The treated mice had enhanced enteric neuromuscular function and showed an altered bacterial community related to autoimmunity — changes that demonstrate a link between

"If you are able to use this method to manipulate the microbiome, you are able to slow down the progression of the disease. We are not saying we can completely cure the disease, but we can make the current animal models live longer, which means you can at least increase the lifespan and the lifestyle of patients." — Jun Sun, PhD

prediagnosis in patients, and limited opportunities to study the disease progression in patients with ALS, researchers used an ALS animal model.

The ALS mice were treated with butyrate or antibiotics to investigate the microbiome and neuromuscular functions.

"We treat them with a bacterial product sodium butyrate because some bacteria products that are beneficial and can suppress a lot of pathogens to simulate a protective role in the intestinal and microbial community," Sun says.

Researchers found the mice had significant alteration of the microbiome, decreased intestine mobility and physical stamina before the onset of ALS. For

the microbiome and intestinal mobility. The enteric neurons also contribute to the development of ALS disease. Those changes happened before weakness in the muscles was diagnosed.

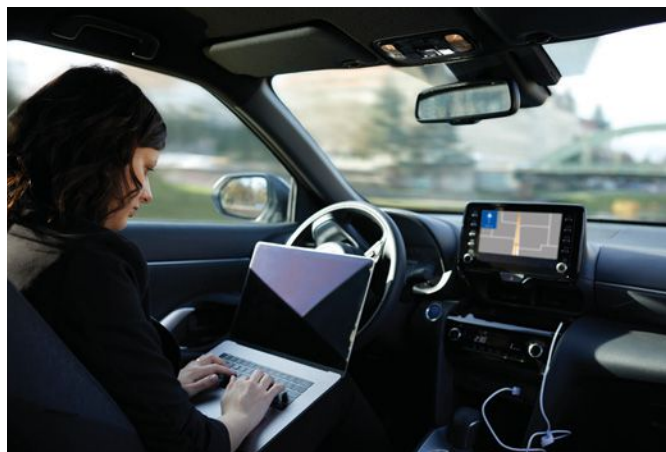
These findings provide insight into the fundamentals of intestinal neuromuscular function and microbiome in ALS, the study states.

"If you are able to use this method to manipulate the microbiome, you are able to slow down the progression of the disease. We are not saying we can completely cure the disease, but we can make the current animal models live longer, which means you can at least increase the lifespan and the lifestyle of patients," Sun says.

Autonomous Vehicle Survey

The Human Engineering Research Laboratories (HERL) at the University of Pittsburgh is conducting a large survey study to help the U.S. Department of Transportation determine how to meet the needs of people with disabilities, older adults (i.e., people over age 65) and their families/caregivers as autonomous vehicles and transportation systems are planned and implemented.

The main focus is the Voice of the Consumer sur-



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vey designed for people living with any disability, anyone over age 65 or care-

givers of both. Additionally, a Voice of the Provider survey for accessible transpor-

tation providers, experts and designers is available.

The survey topic is accessible autonomous vehicles and autonomous transportation systems, such as self-driving cars, automated ridesharing (e.g., Ubers without drivers), etc. The survey takes just a few minutes to complete.

HERL hopes to collect information from up to 2,500 participants by October. To access the survey, visit ctsiredcap.pitt.edu/redcap/surveys/?s=9J8ARE7YL3 or herl.pitt.edu/avsurvey. ■



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ANNUAL AIR RIFLE & AIR PISTOL PROGRAM

Cal-Diego Air Rifle and Pistol Tournament
December 3, 2021
Camp Pendleton
Camp Pendleton, CA

Wisconsin Air Rifle and Pistol Tournament
March 11-12, 2022
Milwaukee Tech Area College
Milwaukee, WI

Mid-Atlantic Air Rifle and Pistol Tournament
March 2022 (Dates TBD)
Colonial Shooting Academy
Richmond, VA

Buckeye Air Rifle and Pistol Tournament *
April 14-16, 2022
Spire Institute
Geneva, OH
**Buckeye Wheelchair Games*

PVA BOATING/FISHING TOUR

Mid-America Bass Tournament
September 10-12, 2021
Lake Eufaula
Eufaula, OK

Vaughan Bass Tournament
October 8-10, 2021
The Lakes of Egypt
Marion, IL

Southeastern Bass Tournament
October 15-17, 2021
Thurmond/Clarks Hill Lake
Evans, GA

Florida Gulf Coast Bass Tournament
April 1-3, 2022
Lake Toho
Kissimmee, FL

Kentucky-Indiana Bass Tournament
April 22-24, 2022
Lake Barkley
Kuttawa, KY

Mid-Atlantic Bass Tournament
June 10-12, 2022
James & Appomattox Rivers
Hopewell, VA

Capital Clash Bass Tournament
June 17-19, 2022
Potomac River
Waldorf, MD

ANNUAL PVA/NWPA BILLIARDS TOURNAMENT SERIES

Buckeye Billiards Tournament
July 17-18, 2021
8 Ball Sports Bar & Billiards
Columbus, OH

Mid-South Billiards Tournament
October 15-16, 2021
Clicks Billiards
Memphis, TN

Mid-Atlantic Billiards Tournament
March 18-20, 2022
Diamond Billiards
Midlothian, VA

ANNUAL PVA/AWBA BOWLING TOURNAMENT SERIES

Great Plains Bowling Tournament
July 29-August 1, 2021
Thunderbowl
Council Bluffs, IA

Mid-Atlantic Bowling Tournament
September 24-26, 2021
Bowl America
Midlothian, VA

Florida Gulf Coast Bowling Tourn.
February 23-25, 2022
Pin Chasers
Tampa, FL

Vaughan Bowling Tournament
April 2022 (Dates TBD)
Bowlero
Romeoville, IL

PVA NATIONAL SHOOTING SPORTS CIRCUIT

North Central Trapshoot
September 11-12, 2021
Crooks Gun Club
Sioux Falls, SD

Cal-Diego Trapshoot
March 25-27, 2022
Redlands Shooting Park
Redlands, CA

Nevada Trapshoot
April 1-3, 2022
Clark County Shooting Park
Las Vegas, NV

Florida Gulf Coast Trapshoot
May 13-15, 2022
Silver Dollar Trap Club
Odessa, FL

Vaughan Trapshoot
June 3-5, 2022
St. Charles Sportsmen's Club
Elburn, IL

Wisconsin Trapshoot
June 10-12, 2022
Brown County Sportsman Club
Green Bay, WI

Iowa Shooting Trapshoot *
June 17-19, 2022
Otter Creek Sportsman Club
Cedar Rapids, IA
**Year-End Tournament*

Mid-Atlantic Trapshoot
(Dates TBD)
Conservation Park of Virginia
Charles City, VA

BOCCIA

KY-IN Boccia Tournament
July 17-18, 2021
Indianapolis, IN

KY-IN Boccia Tournament
September 25-26, 2021
Bowling Green, KY

Bayou Boccia Tournament
February 11-12, 2022
Gulfport, MS

Buckeye Boccia Tournament *
April 14-16, 2022
Geneva, OH
**Buckeye Wheelchair Games*

Mid-Atlantic Boccia Tournament
May 2022 (Dates TBD)
Richmond, VA

Vaughan Boccia Tournament
(Dates TBD)
Carol Stream, IL

HANDCYCLING

Echelon Racing League ToAD Virtual Criterium Races
November 2021 -February 2022

PVAR High Performance Camp
January 29 – February 3, 2022
Brooksville, FL

Museum of Aviation Marathon
January 15, 2022
Warner Robins, GA

Carbonbike USA
February 5-6, 2022
Gainesville, FL

Valley of the Sun
February 18-20, 2022
Phoenix, AZ

Off-Road Spring Expo
April 13-16, 2022
Chesterfield, VA

Redlands Cycling Classic
April 20-24, 2022
Redlands, CA

Gettysburg Marathon
April 2022 (Dates TBD)
Gettysburg, PA

Tour of America's Dairylands
June 2022 (Dates TBD)
Milwaukee, WI

Wichita Omnium
June 2022 (Dates TBD)
Wichita, KS

NATIONAL VETERANS WHEELCHAIR GAMES



July 7-12, 2022
Tempe, AZ

9-Ball Victors

Jeff Dolezal and Joe

Dowling each captured titles at the March 18–20 Paralyzed Veterans of America Mid-Atlantic Chapter's Charles "Chuck" Willis Memorial Wheelchair 9-ball championships in Midlothian, Va.

Dolezal won the Main Event title, with Mark Jones placing second and George Holscher in third. Dowling won the Second Flight division, with Jimmy May in second and Johnny Holland in third.



Second Flight winner Joe Dowling, left, Second Flight runner-up Jimmy May, center, and Main Flight winner Jeff Dolezal, right, pose for a photo at March's Paralyzed Veterans of America Mid-Atlantic Chapter's Charles "Chuck" Willis Memorial Wheelchair 9-ball championships in Midlothian, Va.

Citrus Slam Winners

Anglers Arthur Hunt and

Daniel Kowalewski Sr., each recorded double-digit total pounds of fish and took home titles at the April 1–3 Paralyzed Veterans of America (PVA) Citrus Slam at Lake Toho in Kissimmee, Fla., hosted by the PVA Florida Gulf Coast Chapter.

Hunt and boat partner Royce Andrews captured the Team Division title. They finished with 18.64 pounds, more than 3 pounds ahead of angler



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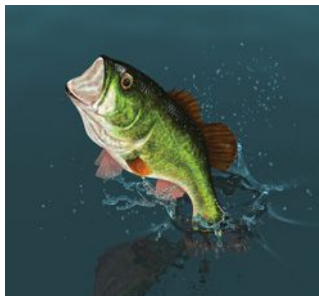
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ParalyzedVeterans



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Ferlin Widowski and boat partner Chris Miller (15.04 pounds) and angler Ted Liefer and boat partner Travis Pugsley (12.83 pounds).

Meanwhile, Kowalewski (New Port Richey, Fla.) won the Open Division title. He finished with 12.64 pounds, while Paul Julian (New Castle, Pa.) placed second with 9.31 pounds and Daryl Newton (Triangle, Va.) was third with 9.28 pounds.

Additionally, Kenneth Burke (Louisville, Ky.) won the Day 1 Bank Division individual title, being the only one of four people to catch a fish. His 1-pound total won it, with Susie Lane (Balch Springs, Texas), Stephen Bush (Tampa, Fla.) and Michael Murphy (Shelbyville, Ky.) tied for second.

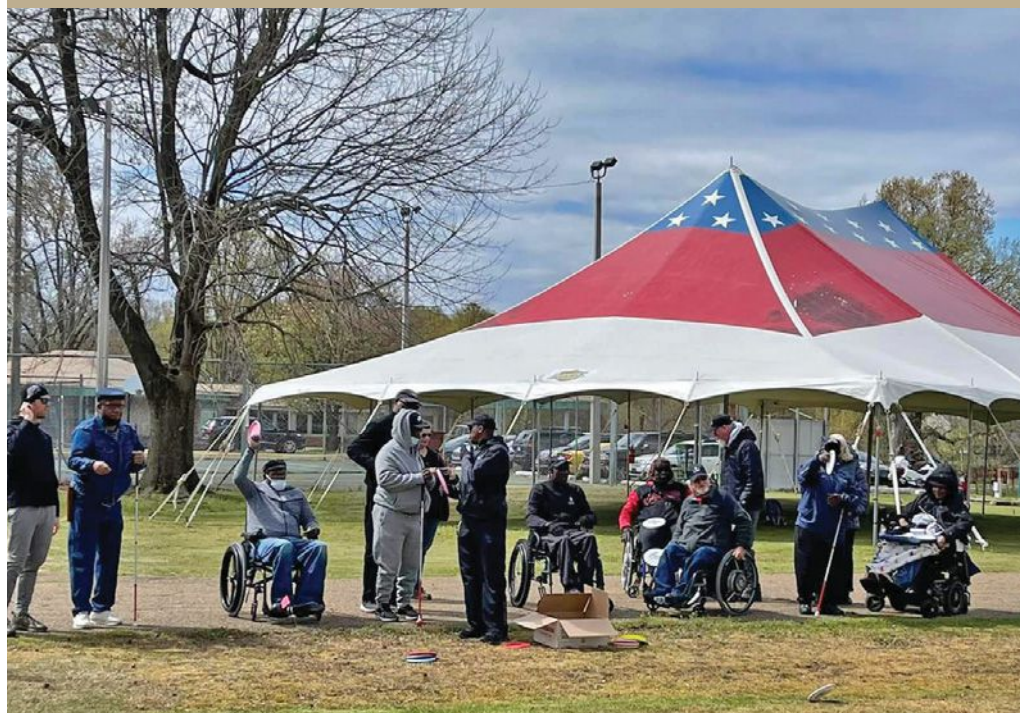
Lane and Bush won the Day 2 Bank Division team title. They teamed up to catch 5.02 pounds, defeating Murphy and Burke (0.00 pounds). ■



COURTESY OF PARALYZED VETERANS OF AMERICA

Disc Golfing In Memphis

Paralyzed Veterans of America (PVA) hosted an April wheelchair disc golf clinic at All Veterans Golfplex and Adaptive Sports Park in Memphis, Tenn., put on by the PVA Mid-South Chapter. PVA's wheelchair disc golf program is supported by a Department of Veterans Affairs adaptive sports grant.



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The Story of “Old Glory”

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- June 14 was selected as Flag Day because it's the day the Second Continental Congress adopted the flag of the United States in 1777.
- The Humphrys Flag Company in Philadelphia made the largest U.S. flag ever in 1992. It was 505 feet by 255 feet, weighed more than a ton and was displayed over the Hoover Dam in Nevada.

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