

**BUT MOSTLY,**

# THE GOOD, BAD AND UGLY OF AIR TRAVEL FOR INDIVIDUALS WITH SPINAL MUSCULAR ATROPHY



**A CURE SMA REPORT ON THE AIR TRAVEL NEEDS AND CHALLENGES OF THE SMA COMMUNITY**



## EXECUTIVE SUMMARY

Individuals with spinal muscular atrophy (SMA)—a neuromuscular disease that significantly impacts physical strength—often travel long distances to attend work meetings, participate in clinical trials, or reconnect with family and friends.

While air travel may represent the most obvious travel option due to distance, many adults with SMA and families with children with SMA avoid or only reluctantly travel by airplane due to uncertain, unsafe, and unsatisfactory past experiences. These challenges include lost or damaged wheelchairs, injuries during transfers in and out of the aircraft seats, inaccessible lavatories, and an overall experience that is stressful, humiliating, and, sometimes, dehumanizing.

Cure SMA—which represents individuals with SMA and their families—developed this nationwide report to highlight the good, but mostly, bad and ugly air travel experiences of the SMA community. Adults and families with SMA from across the United States shared their first-person air travel accounts to help educate Congress and the Administration about persistent air travel challenges and the need for immediate improvements and long-term changes.



# SMA COMMUNITY RECOMMENDATIONS

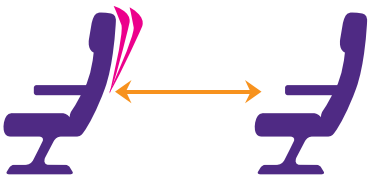
Based on feedback and experiences of the SMA community, Cure SMA recommends the following actions to improve the air travel experiences for individuals with SMA and other disabilities:



**Require Better Training and Equipment:** Individuals with SMA and their families report a significant lack of knowledge, training, proper equipment, and consideration by airport and airline staff during all aspects of the air travel experience. One adult with SMA said, *“Many problems I encounter arise from airport and airline staff not knowing process or rights that I have a person with a disability.”* Cure SMA recommends that the U.S. Department of Transportation develop a training protocol on wheelchair handling and storage (including on specialized lift equipment), passenger transport and transfer, and disability etiquette that the Transportation Security Administration (TSA) and all airlines would be required to certify completion annually by all their staff. This annual training must include in-person, hands-on training components and be developed in partnership with disability stakeholders. In addition, DOT should require that specialized lift equipment be available and used when storing power wheelchairs into the cargo of the plane.



**Improve Dedicated Boarding Process:** Individuals with SMA and their families report that the current boarding process is inadequate, when provided, because it does not allow people with SMA and their families enough time to transfer into the airplane seat and store medical equipment and other belongings. *“It’s not uncommon for the disability seating to be immediately followed on the plane by their premier status individuals who are breathing down our backs as we try to navigate the jet bridge, the entrance to the plane and down the aisle to our seats,”* said a parent of a child with SMA. Cure SMA recommends that airlines ensure the needs of people with disabilities are met during the dedicated disability boarding before starting other stages of the boarding process.



**Increase Seat Pitch and Size:** Individuals with SMA and their families struggle with the current size and pitch of airplane seats. In single aisle aircraft, the person with a disability is placed in the aisle seat and usually are first to board and the last to exit the plane. As a result, other passengers from that row must climb over the individual to get past, resulting in bottlenecks and injuries. There is also limited room for an aide or airport staff to assist during a seat transfer. *“All of my most difficult and most dangerous transfers from a plane seat to aisle wheelchair have come from not having enough room between seats for someone to be on either side of me,”* said an adult with SMA. Cure SMA recommends that airlines increase seat pitch and size to accommodate the needs of travelers with SMA and other disabilities.



**RESTROOMS**

**Require Large, Universal Accessible Bathrooms:** Most adults with SMA and families of children with SMA said the inability to use the airplane bathroom was a top reason for avoiding air travel. Individuals with SMA who do travel by air report taking several precautions before boarding an airplane. *“I am forced to eat and drink as little as possible before and during the flight because I am unable to get to the bathroom during the flight,”* said an adult with SMA. The SMA community also reports challenges with accessible aircraft bathrooms. *“It was almost impossible to fit two people in an airplane bathroom without getting hurt,”* said an individual with SMA. Cure SMA recommends that all aircraft be equipped with an accessible bathroom large enough for people with disabilities who may need the assistance of an aide.

# SMA COMMUNITY RECOMMENDATIONS



**Securement Systems and Wheelchair Containers in Cargo Hold:** Despite enormous precautions, including bubble-wrapping their wheelchairs, mobility device damage is prevalent among air travelers with SMA—and a primary reason many individuals with SMA and their families avoid or minimize air travel when possible. One adult with SMA said, “Airlines are not equipped to keep my wheelchair safe in the cargo portion of the plane.” Damage includes broken joysticks, twisted wheels, and other mangled and bent parts. “When they put his wheelchair in the cargo area, something must have fallen on one of the wheels because it was bent,” said one parent with a child with SMA. Several individuals with SMA recommended dedicated storage areas for wheelchairs “so that checked chairs can be safely handled and secured,” as one adult with SMA put it. Cure SMA recommends that the aircraft cargo hold be fitted with tie down securement systems and containers to safely store and protect wheelchairs from damage. In addition, Cure SMA recommends that aircraft cabins be retrofitted with these restraint systems to prepare for wheelchairs in the cabin.

**Allowing Wheelchairs on the Airplane:** The top air travel priority of individuals with SMA and their families is the ability to use their own wheelchair as their aircraft seat. “Allowing passengers to remain in their wheelchairs would reduce risk of injury to the person with the disability as well as airline staff and would also reduce the risk of damage to wheelchairs.” Cure SMA recommends that new and existing aircraft should include a removable passenger seat and a restraint system for power wheelchairs, similar to other modes of transportation.



**The SMA community recognizes and commends the air travel improvements that have occurred since the passage of the Air Carrier Access Act. However, more can and must be done to increase accessibility and improve the travel experience for air passengers with SMA and other disabilities.** “Flying does not feel like a means of transportation as much as it feels like a horrible and unfair gamble,” said one person with SMA. A mother of an adult child with SMA said, “When the pilot says, ‘sit back, relax and enjoy the flight’, that ought to refer to everyone!” Truly accessible air travel—being able to sit in your own wheelchair on the airplane—would open air travel for all individuals with SMA and other disabilities. “Allowing wheelchairs on the airplane must become a reality because it will unlock the world for all folks with disabilities,” said an adult with SMA. Another person with SMA shared a similar view: “Being able to roll or drive onto the aircraft would allow me to finally access everything this beautiful country has to offer.” The first-person experiences and recommendations included in this report are aimed at achieving the goal of equal access to and experience with air travel for all passengers, with and without disabilities.

# AIR TRAVEL EXPERIENCE SUMMARY

## THE GOOD, BAD, & UGLY

### THE GOOD



- “I had an EXCELENT trip in 2018 thanks to the disability advocate associated with the airline. She met me on my day of travel and guided me all the way through the airport until I was safely on the plane and my chair was stowed. She gave me detailed instructions and expectations of how to handle my time flying from the moment I arrived curbside at the airport until leaving the doors of my destination’s airport.”
- “A good travel experience involves a quick check-in at the main desk, easy confirmation that my service dog is all set, confirmation that the aisle chair will be at the gate, a female TSA officer available for pat-down, the ground crew available to come talk to me about how to handle my chair and not being rushed during boarding.”
- “From the time I arrived at the airport, I was well informed of things that would impact me (arrival of a wheelchair assistant, boarding accommodations, flight attendant confirming proactively that a wheelchair would be waiting for me at the gate, assistance with my luggage by the wheelchair attendant that transported me to my transportation).”
- “The aisle chair transfer went smoothly because I was fortunate to receive a skilled attendant at the airport. This is the first time the airport staff knew how to transfer me, given the severity of my physical limitations.”
- “The first time I flew on an airplane with my wheelchair, the flight crew was very kind and understanding. They made sure my needs were met and that my wheelchair was not damaged. They took extra caution to ensure I would have a good experience, and it certainly worked out!”

# THE BAD & UGLY

## WHEELCHAIR DAMAGE



- “We loaded into the plane and while we were sitting at the gate, I watched the ground crew throw my wheelchair seat on the ground while it was raining and then 4 men flung my chair on its side on the conveyor belt. When we landed, they brought my wheelchair to the gate only to discover that it was non-functional. The chair had no power, and the joystick had an error code on it. The chair would not move at all. The repairs to my chair were over \$3000. It was the most humiliating and frustrating experience of my entire life.”
- “One time, I was seated by a window overlooking the loading area and watched as the loaders ignored the instructions that I taped to both sides of the wheelchair for how to initiate the brakes. They proceeded to wrenching it around by some of the weakest points and broke the controller arm in half.”
- “When my son was 3, he had a tiny manual wheelchair. The airline put his wheelchair in the cargo area where something must have fallen on one of the wheels because it was bent. We were never able to get the wheel straight again and he wasn’t able to push it by himself anymore due to his decreased strength.”
- “On one trip, my chair was damaged to the point I couldn’t function in it. It was not able to go up or down or recline which I use to breathe right. It was not able to drive far without needing a break. I was in pain for 8 months while it underwent repair.”
- “Once I had my entire chair mangled and mishandled after being treated poorly. The gate attendant didn’t provide any advance entry to the plane and didn’t get ground operations to my wheelchair before I was forced to leave it on the jetway and get carried onto the plane. The ground crew broke the armrest which held my joystick and upon getting to the destination I had no working wheelchair.”
- “My son was forced to leave his power wheelchair at check in and sit in a manual chair that was completely inadequate for him and miles too big. I had no option but to sit in the chair and hold him to keep him from falling out. Prior to arrival, a member of the flight crew came to us and informed us that my son’s chair did not make it on board. As soon as it was discovered, they put the chair on the next flight, but we were left without my son’s chair for hours.”

# THE BAD & UGLY CONTINUED

## INJURIES DURING TRANSFERS

- “On one flight, when transferred from the aisle chair into the plane, I had to scream at the transfer folks because they were jamming the armrest into my back. It was so bad the fellow flyers were apologizing and asking if I was ok. I ended up with a huge bruise on my back.”
- “I was put on an aisle chair and the aisles were not wide enough to get someone through easily. I am not a large person. My thighs kept bumping into armrest causing bruising and pain.”
- “The transfer people didn’t lift me properly while transferring me from the aisle chair to the airplane chair and almost broke my arm trying to lift me. While they didn’t break it, they did injure me by pulling a muscle in my shoulder.”



## INACCESSIBLE LAVATORY & OTHER BARRIERS

- “Our children have to hold their urine and bowels while flying which is unsafe and highly uncomfortable. They experience increased stress because they’re worried about having an accident on the flight. It really feels inhumane that they are not able to sit safely or comfortably on the plane or use the bathroom like everyone else.”
- “On one flight, I was stuck on the gate/tarmac because of rain. Everyone else on the plane was allowed to deplane and relax outside the gate and eat and use the bathroom. The pilot told me I could get off, but they would have to unload the plane and reload it when given the clearance and it would delay us more. I chose to stay on the plane to not delay more. We had an 8-hour delay on what was supposed to be a 3-hour flight. The whole time I was stuck on the plane without my custom seating, and I could not use the bathroom. It was hard and I ended up getting a pressure sore and had other health problems from that trip.”
- “It was almost impossible to fit two people in an airplane bathroom without getting hurt. I got hit on the walls multiple times the last time I needed to use one.”
- “Restrooms on a plane are a major issue. Because my sons are older now, I cannot safely get them in an airplane restroom as currently constructed. We have to limit the lengths of our flights, or my sons will have to wear diapers.”
- “If there were bathrooms on board that could accommodate a wheelchair user AND their companion, that would be ideal.”



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## ABOUT SPINAL MUSCULAR ATROPHY

SMA is a degenerative neuromuscular disease that robs people of physical strength, taking away their ability to walk, eat, and breathe. SMA impacts 1 in 11,000 births in the United States and an estimated 1 in 50 people is a genetic carrier. If both parents are SMA carriers, every child they have together has a 25% chance of being diagnosed with SMA, regardless of race, ethnicity, and gender. With three effective U.S. Food and Drug Administration-approved SMA treatments and advances in SMA care, individuals with SMA are achieving unprecedented milestones and stopping or slowing the degenerative course of the disease. However, individuals with SMA, especially those who received treatment after symptoms appeared, may require medical care, mobility assistance, and caregiving support for their health and independent living.

## ABOUT CURE SMA

Cure SMA is the leading national organization that represents individuals with SMA and their families across the United States. Cure SMA educates and advocates for policies and legislation that promotes independence and community living and protects access to care, treatment, and services for all individuals with SMA. Cure SMA also funds SMA research and supports the SMA community by hosting educational conferences and workshops and managing equipment pools and other support programs.



## ALABAMA

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### LINDA (GADSDEN, AL)

“The last time we flew overseas, the flight attendant allowed us to use the first-class bathroom and we had to leave the door open while using it, as it was too small. That is beyond embarrassing and would not fall within any health safety measures.”

### REBECCA (HOOVER, AL)

“I travel by air about once a year but prefer to travel by car. The majority of my air travel has gone well. Most gate agents are kind and considerate of my travel needs. I can still walk to the seat. For me, having specific seats available that have more room to accommodate braces and other adaptive aids would be helpful. Also, the plane should have wider aisles so if a restroom visit is needed you could navigate the aisle easier with a cane or walker.”

### PETER (VESTAVIA, AL)

“I travel by air two times a year to visit family in MA and Ireland. Otherwise, I will drive 7 or 8 hours domestically to avoid travel. Using a wheelchair is a difficult experience with airlines. From the security process with TSA to being the 1st on and last off a plane, the experience is horrible. Airlines need trained professionals who can lift properly.”

## ALASKA

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### PATRICK (ANCHORAGE, AK)

“I travel with a ventilator, POC and other medical equipment, I have received a waiver from the FAA/DOT for lying down during the flight. I generally do not have trouble getting certain assistance.”

## ARIZONA

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### MINDY (BUCKEYE, AZ)

“I absolutely love to travel and my soul longs to see the world. I would also love for my son to benefit from the growth that can only come from experiencing other cultures and lifestyles around the world. Unfortunately, air travel is extremely difficult when you rely on others to not only handle your wheelchair (aka legs), but to have staff literally lifting you to get to the seat. I, and all other wheelchair users I know, would be forever grateful if Congress made air travel more accessible.”

### MARGARET (GILBERT, AZ)

“Those of us who have to use a power wheelchair and like to travel by air do so without confidence or reassurance that our “legs”—used for daily independence and mobility—will arrive undamaged. We are also riddled with anxiety about the often unsafe transfer from aisle chair to the even more often uncomfortable airline chair.”

### MARCIA (GOODYEAR, AZ)

“I travel 3-4 times a year and the airlines are good about understanding my disability at the airport. I am unable to take my mobility scooter out of concern for potential damage if gate checked and issues with batteries. I use wheelchair transport to the gate. The tight seats in the aircraft make it difficult for me to get up from my seat. Wider seats would help me move into position to get up and increased seat pitch would mean I would not have to get up when others in the row need to go to the restroom.”

### RONALD (PHOENIX, AZ)

“I used to fly bi-monthly for meetings involving my work. Eventually, I had to give up air travel do to successive and numerous personal injuries that occurred during transfers to and from aisle chairs, and 4 successive flights that rendered my custom power chair unusable and a 5th where the chair had to be repaired after a TSA search.”

## ARKANSAS

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### KHI (MAUMELLE, AR)

“I do not travel as often as I would like because airlines make it very difficult to fly as a disabled person. For example, in June of 2022, the airline lost my wheelchair to a connecting flight. We had to wait an hour for them to find it. Then, on our flight home, the flight attendant would not allow my mom to get back on to help me transfer. These problems would disappear if wheelchairs were allowed during the flight.”

## CALIFORNIA

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### TAMMI (CITRUS HEIGHTS, CA)

“I choose NOT to travel by air anymore because of the damage that was done to my wheelchair previously by the airlines, and because my physical disability has progressed to the point that I am not able to safely transfer or sit in the aircraft seat. On one flight, my wheelchair was damaged to where I could not put the footrest back on the wheelchair. The airline did not take responsibility, which left me feeling stuck and abandoned. If I could roll my wheelchair onto the plane, I would fly to the ends of the earth!”

### DAN (DANVILLE, CA)

“The airlines I’ve traveled with have a history of mistreating my wheelchairs and breaking them, and it is difficult for me to breathe when sitting in a regular airline seat. When I went to Hawaii for my high school graduation present, we arrived early at the airport to meet with TSA and told them how to handle the chair. Right before we boarded, we wrapped the chair with cellophane, and they took the chair down to the tarmac. When we got on the airplane, we saw them pick up the chair after we told them that the chair should be lifted with a forklift. As a result of this action, my wheelchair was damaged when we arrived in Hawaii. This affected my entire trip and experience thereafter. As well as all of this, the pilot announced over the intercom that the flight was delayed due to having to load my chair into the cargo bay. So not only was I embarrassed and blamed in front of a plane full of strangers, but I was made to feel bad for being disabled on top of mishandling my chair and the fallout related to that misstep.”

### KRISTIN (LIVERMORE, CA)

“Our family cannot travel by air for vacations or clinical trials because our daughter cannot sit in an aisle wheelchair, cannot be safely transferred to an airline seat, and cannot sit in anything other than her custom power wheelchair seat for any length of time. Just the hassle of dismantling our daughter’s power chair and wrapping it with cling wrap (both coming and going), carrying a special needs car seat (that she really wasn’t comfortable in), and carrying her down the aisle was too much for us. Being able to fly with her wheelchair would allow our family to go on family vacations out of state, visit with out of state family members (that she hasn’t seen in years), and allow our daughter to participate in out of state clinical trials.”

### SHRIYA (LIVERMORE, CA)

“Inaccessibility is the reason we don’t travel more than 2-3 times a year. Our wheelchair should be returned to us in a timely manner at the gate and in the same condition we checked it. This happens on occasion, but we often experience horrible wait times, and the chair is returned damaged at the gate. Wider aisles and more supportive seats for passengers with physical disabilities would improve air travel accessibility.”

### ALEXA (LOS ANGELES, CA)

“I fly to the east coast 2-3 times a year to visit my family. It is extremely difficult for me to sit independently in a regular airplane seat. As a result, I am in physical pain for the duration of my flight. Moreover, I am not able to sit independently without the assistance of a care attendant. Subsequently, I am forced to purchase 2 tickets, doubling the expense of my travel. On multiple occasions, the airline has dropped my wheelchair and broken it. As a result, I lost my means of mobility for weeks at a time while repairs were completed. Breaking the mobility device of a wheelchair-user is akin to chopping off the legs of an able-bodied individual. If I were to remain in my wheelchair, as I do on buses and trains, I could travel independently.”

### JODI (MORENO VALLEY, CA)

“I find air travel uncomfortable because I don’t have my custom-fitted chair to help relieve pressure, the ability to raise my legs up to reduce swelling, the ability to raise and recline my seat to a more comfortable seated position. The ‘aisle chair’ is extremely uncomfortable and does not always work with the SMA body type. That’s why I don’t fly very often.”

### NIKKI (SAN CLEMENTE, CA)

“We love to travel but air travel is difficult with our 10-year-old son who is in a wheelchair. We traveled to Cabo San Lucas and, despite calling several times in advance to arrange all aspects of the travel with my son’s wheelchair, when we arrived in Cabo they did not have a ramp for deplaning, only stairs that led to the tarmac. Both times, the pilot and crew seemed confused upon landing and could not obtain a ramp. My husband had to carry my 75-pound son down the stairs. After it happened the first time, I called numerous times and was assured the proper arrangements were made the second time. But instead, it happened again despite our best efforts and due diligence.”

### JEANETTE (SAN JOSE, CA)

“I travel 4-8 times a year. Once, I was dropped being transferred to an aisle chair and the pilot helped get me off the floor. Then I was transferred to the airplane seat and on the way my butt hit the armrest giving me a bruise. When on the plane I couldn’t call for help because I couldn’t reach the call button. The plane was delayed and that meant no bathroom for a few more hours. At the airport, they lost my wheelchair for 2 hours. When my chair was returned, it was damaged, and I had to wait forever for repairs. I had to wait in a different chair, which was painful and didn’t allow me to get around. People had to help me with everything like pushing me around or positioning me because the loaner chair couldn’t recline. It was very stressful and embarrassing.”

### **SAM (SAN JOSE, CA)**

“We have traveled 4 times in the last 3 years and the experience for my son and us as parents and caregivers was horrible. The waiting for his power chair takes too long especially when they say they don’t know where it is. They should be able to stay in their own chairs while traveling. Why after all these years has it not been accomplished? It would increase our chance of flying more.”

### **ANGIE (SANTA CLARA, CA)**

“During one bad experience, the airline refused to gate check my electric wheelchair. Due to severe disability, I am unable to safely sit on manual wheelchairs provided by the airport, which lack head/chest support. But the airline insisted I take such a manual wheelchair. Upon landing, I requested to stay in my plane seat (which does have head support and seatbelts) until my electric wheelchair was brought to the gate. The airline once again stated they do not provide gate-to-gate services for electric wheelchairs and threatened to call security. The airline eventually arranged for my electric wheelchair to be brought to the gate. In other situations, I’ve had my wheelchair returned to me in a damaged state. I’ve had airlines refuse to bring my chair to the gate and hence had to ride the plane aisle chair all the way to baggage claim. I’ve been forced to transfer to an aisle chair in public, at the gate, with everyone staring.”

### **KIM (SANTA CLARA, CA)**

“I travel about four times a year because of family vacations, family events, conferences, and school events. Honestly, with the current system, there are not many good stories to share. It is always a nerve-wracking experience. 1. Airport crews don’t know how to deal with the power chair. They are very hesitant (or refuse) to bring a wheelchair to the gate. 2. My wheelchair got damaged after the flight 3. Airport crews expressing anger in front of us about how frustrating it was to push the chair to the gate. 4. Being carried to/from aisle chair in front of many people. 5. Seating in an aisle chair unsupported 6. Seating in a passenger seat without proper support. 7. Not being able to go to the bathroom because there is not enough space to be laid to undress without the wheelchair 8. Not being able to eat because the passenger cannot eat without the proper support. If the wheelchair can be taken onto the aircraft, the passenger can sit safely with the proper support, eat/swallow properly, no pain from the pressure, being able to sleep. Also, it will be helpful for the airport crew who must carry this chair up and down.”

### **RYAN (SLOUGHHOUSE, CA)**

“I travel by air roughly 5 times a year for various reasons like work, vacation, and general travel. I have a standard procedure whenever I travel by air, and it starts with checking in with my airline at ticketing. Once I get to ticketing, I fill out all the necessary information like how much my chair weighs, etc. I request to speak with the ramp supervisor once I arrive at my gate. After checking in at ticketing, I check in at the gate of my flight and speak to everyone there that assists me. Part of flying is also being able to board first so that I can have all the space I need when transferring. Once I am boarding and near the plane door, I speak with the ramp supervisor about all the parts of my chair. I tell them that I take off all of the essential pieces and bring them on the plane myself. This includes a touchscreen joystick remote console (est. \$1,000), my headrest, and my side thigh guard which I use for bathroom access. After this, I say that the chair does not fold or collapse (we zip tie signs that say this in ALL CAPS) and show them how to put the chair in manual mode since it will not drive without the remote console. 99% of the time when I go through all of these steps, my chair remains in one piece other than for minor scratches and parts that need to be adjusted.”

### DREW (TORRANCE, CA)

“Our wheelchairs are designed specifically for our unique bodies and are fitted by occupational and physical therapists. They keep us safe, comfortable, and in control of our comfort. Allowing wheelchairs on the airplane must become a reality because it will unlock the world for all folks with disabilities to travel without fear of having their ‘legs’ broken, and travel in comfort, which is what most folks also cite as their reason for not flying. I wish I could travel more often but the inherent risk doesn’t allow me the freedom I desire. As a result, I travel as little as possible, mainly due to risk of breaking the wheelchair.”

### JENNI (VAN NUYS, CA)

“I no longer travel by air because of past damage to my electric wheelchair. Now that aircraft often have long delays in which you can’t get off the airplane and there are no accessible bathrooms on aircraft, it makes it not feasible. Being able to use my wheelchair on the aircraft would make all the difference in the world.”

### SARAH (WILLOWS, CA)

“We have family back east, so we need to fly to visit. We don’t go as often as we would like in large part due to the difficulty of flying. I have been physically hurt, my chair damaged to the point that my trip was ruined, held up a plane taking off (and the flight attendants announced to the entire group of passengers that I was the reason the flight was leaving late even though it was the flight crew that delayed taking my chair for transport). I would fly much more often, with far less anxiety, and more comfort because I would be seated in my chair rather than transferred. I could also fly alone instead of having someone else travel with me.”

## COLORADO



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### GABY (LITTLETON, CO)

“I travel about three times per year; nationally and internationally. Always with my family, never alone. It is very hard for my dad to lift me up by himself. My mom or brother must be around to help. I don’t think it is safe for anybody. Me, my father, or anybody involved. It would be incredible to be able to be in my own chair in the airplane. The chair I am in 24/7. The chair that helps me position my neck, hips, and legs. The chair that knows all my curves and was made exactly for me to be comfortable. It would be a dream come true.”

### JENNA (MEAD, CO)

“My son requires the support of his personal wheelchair and the space for his medical equipment that is built into his chair. He cannot sit upright unassisted and is unable to fly due to the requirement to get out of his chair.”

### KATE (PAGOSA SPRINGS, CO)

“We travel by air once a month for medical appointments. On the best travel days, staff are attentive, we receive priority boarding, and even seat upgrades to help the onboarding process. On one bad travel day, it took 45 minutes to get her chair unloaded from cargo so we could deboard the plane. There was no aisle chair available to get on or off the plane during the delay. Had to piggyback during deplaning.”

## CONNECTICUT

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### GABRIELLE (MYSTIC, CT)

“My daughter with SMA absolutely loves to fly but we haven’t travelled on a plane since 2016. She doesn’t like the hassle of transferring into an uncomfortable economy seat and being out of her custom chair. As she has grown (now an adult), the transfers have become too difficult even with extra help. When we traveled, she would park her wheelchair right at the gate of the aircraft, and with our own tools, we’d remove all of the components and stow them in a separate carry-on for safe keeping, then reassemble the chair upon arrival before she could get into it again. Once onboard, we would carry her to her seat and wedge her into the window seat so she could lean against it. Her feet couldn’t touch the floor of the plane and the airline would not allow her to have a bag under her feet for support during take-off and landing. She would go to sleep resting her head against the tray table on the seat in front as the seats didn’t conform to her body (she has titanium rods in her back). The thought of traveling is daunting and worrying if the wheelchair will arrive in one piece. Getting her out of the window seat to use the bathroom was very difficult also. Back breaking to say the least.”

### BRANDON (THOMASTON, CT)

“I have not traveled by air since my last experience in 2002 because of my health and all the restrictions since 9/11/2001. Before 9/11 it was tolerable because I was able to make trips to Florida from Connecticut in an airplane seat without problems. However, I can no longer transfer to an airplane seat because of my low lung capacity (8%) and history of thrombosis. I use a custom seat in my wheelchair which makes sitting and breathing much easier. Having the ability to use my wheelchair as my in-cabin seat would definitely open my option to fly again. It would also give me a chance to explore international countries rather than doing all my traveling via road trips.”

## DELAWARE

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### NATALIE (WILMINGTON, DE)

“I don’t travel by air often because of damage to my wheelchair. Airlines repeatedly break a piece, part, or entirety of my wheelchair every time I get it back after it has been put under the plane. One time after arriving at my destination, the entire foot plate on my wheelchair broke off and fell to the floor while I was maneuvering it out of the airport. The foot plate is a very important aspect of my chair as it is connected to multiple wires. Because of its damage, it immediately shut down the entire operation of the chair and I was not able to move. Luckily my family was with me. They had to push me and my 300lb chair out of the airport. I was stuck for a while because I was no longer in my home state and had to find help in a new community.”

# FLORIDA



## THOMAS (ALACHUA, FL)

“I travel a few times a year but would travel monthly for work if I could stay in my chair. I was dropped and got the airline to settle.”

## JOHN (BOCA RATON, FL)

“I have only traveled by plane twice in my 25 years. I avoid air travel because damage to my wheelchair would be catastrophic. My wheelchair got damaged both times I flew. On one trip, my power wheelchair brake that releases to manually push my chair was broken. My parents were unable to push the chair. Additionally, my joystick that is perfectly positioned to allow me to drive my chair was completely out of position and I was unable to drive independently until it was fixed. Being able to roll onto an airplane with my wheelchair would be an absolute dream come true. I just want the same opportunities to fly like everyone else.”

## MONICA (DAVENPORT, FL)

“I only travel every few years. I haven’t had a bad experience yet, but I advocate for myself by telling the airline what accommodations I need as far in advance as I can. I recommend that you inform the airline of the accommodations you will need as far in advance as possible and ask the airline or check the FAQ’s and the FAA website if you have any questions regarding traveling with a disability.”

## JOSE (FORT LAUDERDALE, FL)

“I use air travel at least 3-4 times a year typically for business. On one trip, the airline dropped my wheelchair while 4 guys were trying to take it out of the belly of the plane. It cracked the entire body frame of my wheelchair along with my EZ lock (which is the mechanism on the bottom of my wheelchair that allows me to lock-in while driving my car). There was another time when the transfer people didn’t lift me properly while transferring me from the aisle chair to the airplane chair and almost broke my arm trying to lift me. While they didn’t break it, they did injure me by pulling a muscle in my shoulder.”

## ELIZABETH (GULF BREEZE, FL)

“We travel by air with our daughter with SMA a few times a year, mostly for out-of-state medical appointments. We drive whenever we can because we feel so much more in control of what we can do for our daughter. On one flight, the airline broke the brakes on my daughter’s wheelchair. They also had it coming out on a conveyor belt from the back of the airplane where we saw multiple pieces of luggage topple over the side and fall to the concrete. Hers didn’t do that but they clearly shoved it in the cargo hold without regard to what items would shift into it during takeoff and landing. TSA should also be much more accommodating. They couldn’t grasp that my daughter couldn’t walk through the security machines on her own. They wanted all of her assistive gear off, which is embarrassing and cumbersome to take off and put back on. Manual wheelchairs should be able to be kept in the cabin.”

## CIJI (MARGATE, FL)

“We travel 4-5 times a year to see specialists and to see family and for vacation, and advocacy. My daughter requires a lot of equipment. We are grateful when they allow my husband to make multiple trips with the medical equipment to our seat before loading the rest of the passengers. Her medical equipment doesn’t all fit under her seat. Because the seat space is so small, we sometimes pay for an additional seat because of all her medical equipment. On one trip, our stroller was broken. Luckily, my husband was able to fix it.”

## AMBER-JOI (MIAMI BEACH, FL)

“We almost always travel by air. We don’t let SMA hinder air travel, but my daughter is light enough to carry when necessary and has minimal equipment. She is ambulatory but cannot walk far distances. When we disclose our daughter’s disability, we are allowed to pre board to provide more time to walk to her seat as she cannot keep up with the pace of others.”

### ELIZABETH (ORLANDO, FL)

“I do not travel by air as much as I would like. My wheelchair was damaged, and I was in bed for days because I did not have a second power wheelchair.”

### TERRI (PENSACOLA, FL)

“We mostly go places that are within driving distance. On my daughter with SMA’s first flight, the flight attendants were amazing. Airport gate changes with a baby is not easy, especially when she wouldn’t walk.”

### LIELEN (POMPANO BEACH, FL)

“I’ve traveled extensively in the United States, Europe (several countries), and Mexico. They use a special chair to roll me into the halls and transfer me to their seat. Then they take my power wheelchair to the cargo during the travel. My wheelchair was damaged on a flight in the ‘90s, but other trips have gone well. I don’t travel as often in recent years due to economic reasons.”

### JEANA (SAINT JOHNS, FL)

“I was put on an aisle chair and the aisles were really not wide enough to get someone through easily. I am not a large person. My thighs kept bumping into armrests causing bruising and pain. On my preferred airline, I drive my power chair to the plane door. My husband is able to drag me the few steps to my seat. They allow me to sit in the front row and it is wide.”

### SHANI (SURFSIDE, FL)

“I don’t travel so often because it’s super complicated with a wheelchair. On one trip, we were seated all the way in the back of the plane. I had to hold my daughter the whole walk there since they didn’t want to take out the plane wheelchair. They then forgot to bring the wheelchair to the gate and ended up bringing it up with the strollers. Understanding that people with a wheelchair need extra help and assistance would be a helpful start.”

## GEORGIA



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### BENJAMIN (ATLANTA, GA)

“I often choose to drive when I travel because I am unable to stay in my wheelchair and because a damaged wheelchair is the likely outcome of having my chair checked as luggage. I would fly 3-5 times a year if I could roll onto the aircraft with my wheelchair and stay in my wheelchair. Traveling by air is challenging for me because I’ve had my wheelchair damaged and I’m unable to use the bathroom during flights, as I am unable to get from the airplane seat to the bathroom. Domestic planes do not have large enough restrooms.”

### CADEN (CLEVELAND, GA)

“Traveling by air with SMA is painful and the way that airlines currently transfer passengers is unsafe.”



## HAWAII

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### JANELLE (HONOLULU, HI)

“I love travelling, but because I live in Hawaii, I must travel off island by air. Travelling on airplanes is fun, but stressful because air travel is very inaccessible and uncomfortable for disabled individual because: 1) Mobility devices, such as power wheelchairs, are often mishandled, damaged or lost in transit 2) There are no accessible bathrooms on airplanes, forcing those who need assistance to use the bathroom to a) hold their urine/bowel movement or b) find alternative methods to use the bathroom (adult diapers, catheters, etc). 3) Sitting in airplane seats is uncomfortable and we’re unable to board planes with our customized wheelchairs. On one flight, I was forced to sit in an aisle transfer chair for 1 1/2 hours while they located and delivered my wheelchair. The aisle chair was super uncomfortable after a long flight, and I just wanted to use the bathroom.”

## IDAHO

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### CARRIE (BOISE, ID)

“I honestly have not had a good experience the last 6 times I used air travel. Flying is a complete nightmare for anyone in a power wheelchair! The worst experience I had was flying to my uncle’s funeral in California. In preparation for the flight my companion wrapped my chair in plastic wrap & we put instructions for the baggage crew on how to move it and also asked that they take care of it as it is my legs! While on the plane, I watched the ground crew throw my wheelchair seat on the ground while it was raining and then 4 men flung my chair on its side on the conveyor belt. When we landed, they brought my wheelchair to the gate. The plastic wrap had been pulled off and I discovered that it was non-functional. The chair had no power, and the joystick had an error code on it. They gave me a dilapidated bariatric manual wheelchair that was significantly larger than I am, and I couldn’t reach the tires to move myself. I couldn’t do anything. It was a fiasco and a huge embarrassment. My family helped me locate a medical supply business that had a scooter I rented for the 3 days I was in CA. I had no ability to do anything alone during that time plus the scooter didn’t support me, so I was in a significant amount of pain. When I arrived home, I had to immediately address getting my chair functioning as I had to return to work. The repairs to my chair were over \$3000. It was the most humiliating and frustrating experience of my entire life.”

### SHAWN (BOISE, ID)

“One year when traveling with my brother, we were brought a manual wheelchair (mine was loaded on the plane) and my brother wheeled me onto the plane. The old jetway had steep short ramps & the footrests got hung up and I fell out of my chair. My feet got pressure injuries from all of my weight landing on them. No broken bones but my feet were swollen and black & blue for a couple weeks. Aside from that trip, I guess my flights were rather uneventful aside from always having to wait for a wheelchair to be brought to the plane so I could get to my connecting flight. My sister, who also has SMA, has had her power chair nearly destroyed twice. The joystick assembly was broken, and the seat lift (the hydraulic type) was bent to the point where the seat couldn’t be raised or lowered.”

# ILLINOIS

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## ELLEN (BUFFALO GROVE, IL)

“We usually like to travel 2-3 times a year but having to deal with the very small toilet cubicle to help a person with SMA is very hard. Our 9-year-old son with SMA is unable to clean himself so my husband and I have to change his diaper inside the very small cubicle, all 3 of us, and the door has to be totally closed. We were squished inside with a changing table that only fits an infant. Airplanes need bathrooms with enough space for at least 2 people and changing area/table that could accommodate older persons with disability.”

## KIMBERLY (CAROL STREAM, IL)

“I have traveled several times by air with my son with SMA. I no longer travel by air with him because he is now too heavy to be carried and the aisle chairs are not safe for people who need maximum support.”

## BRAD (ELMHURST, IL)

“Getting in and out of aircraft seats is becoming increasingly more difficult for me. Staying in a chair would make me more comfortable to avoid dangerous transfers and lifts for me and my attendant. Upon arrival on one trip, there was no wheelchair attendant to provide a chair and help me off the airplane. The flight crew became increasingly annoyed that I was waiting inside the aircraft for a chair to arrive. They ultimately asked that I get on an aisle chair to be transported up to the top of the jet bridge so they could leave the plane. Unfortunately, no one ever arrived and so we ended up having to use the aisle chair ourselves to get through the airport to baggage claim.”

## KATIE (ELMHURST, IL)

“I do not travel by air. Fear of damage to chair. Fear of staff being able to get me in and out of my seat. Not knowing what help I can receive at airports. Fear of using the bathroom. I traveled about five years ago when I was a bit more mobile and getting wheelchair assistance was difficult. I would fly pretty frequently if I were able to use my wheelchair on the airplane. It would be so comfortable and convenient.”

## JERRY (FAIRVIEW HEIGHTS, IL)

“I never travel by air. I don’t trust the airlines with my wheelchair, nor with my comfort. I have significant pain and circulatory issues which prevent me from sitting in a normal airline seat. I would be more likely to travel by air if wheelchairs in the cabin of an aircraft were a reality.”

## MICHAEL (FRANKFORT, IL)

“I don’t travel by air very often because it is too much of a hassle given my SMA. Having to transfer into and out of the plane seat causes too many difficulties, and if I need to use the bathroom, that’s an ordeal of its own. There was one time I needed to use the bathroom on a flight and getting into and out of the bathroom was a nightmare. My parents struggled to figure out how to get me off the toilet, and I kept worrying I would be accidentally injured in the process. Those bathrooms are way too small for a person with physical disabilities to use, and it caused anxiety for my entire family.”

## DONNA (MENDOTA, IL)

“Due to the significant nature of my disability, I cannot transfer out of my wheelchair. Thus, I can no longer travel by air unless there becomes a way for me to remain in my chair. Many years ago, when I traveled by air because I could transfer out of my wheelchair, several pieces of my wheelchair became bent, scratched, and damaged. Damaged areas included part of the wheels and brake.”

### SHANNON (DES PLAINES, IL)

“I’ve traveled dozens of times by air and have had a number of good experiences where my wheelchair was not damaged, and the gate attendants and flight crew were all nice and accommodating. However, my most recent experience from Punta Cana to Chicago O’Hare included an emergency landing in Orlando that resulted in having no access to my wheelchair, food or water for almost 12 hours. I was stuck in an oversized transport chair that had no head or body support that my custom chair provides. Making matters worse, the airline didn’t put my chair on our return flight. It remained in Orlando for over 2 days. Throughout this situation I was separated from my wheelchair (aka “my legs”) for a total of 54 hours where I was stuck at the airport and then in bed. This whole experience was awful and the way I was treated and the amount of misinformation I received from the airline was unbelievable.”

## INDIANA



### NATALIE (CARMEL, IN)

“I flew 23 hours straight to get to Australia and had to avoid drinking before and on the plane because it was just me and my mom. It’s impossible for her to pull my pants up by herself in the bathrooms the way they are now.”

### JESSICA (HUNTINGTON, IN)

“We only travel once every three years or so, mostly because of costs. When we did travel, the TSA Cares supervisor made getting through security with all of our equipment very smooth and easy. The small space on the plane made it difficult to maneuver and put all of her equipment on/change settings as needed.”

### SHERYL (LAFAYETTE, IN)

“My husband with SMA and I travel four times a year for a clinical drug trial. The airport we fly to continues to be sluggish in getting our chair to us. We have experienced 30-45 minute wait times. And they tell me not to worry when they have no idea where or who is getting the chair. Another airport lost our wheelchair for 1.5 hours!”

## IOWA



### SARAH (PELLA, IA)

“My husband and I travel by air 1-2 times per year, but we feel we have to travel by ground with our family because of the need for an accessible vehicle once you arrive at airport and how our daughter with SMA has to travel straight up in a seat and not risk destroying her chair. If airlines allowed wheelchairs in the cabin on the plane, it would make it possible for our entire family to travel by air.”

## KANSAS



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### AVA (MANHATTAN, KS)

“I very rarely travel by air. It is too difficult.”

### JC (WICHITA, KS)

“It’s been a few years since I’ve travelled by air. I typically avoid air travel for several reasons: 1) there is high risk of damage to my wheelchair, 2) there is risk of wheelchair not being loaded onto the plane at all, 3) I have to sit in an uncomfortable airline seat, 4) I have to rely on strangers to transfer me, and 5) my accessible vehicle will not be at the destination and rental mobility vans are very expensive, not easily accessible, and will not allow me to be the driver due to lack of custom mobility equipment. Until wheelchairs are allowed in the cabin, all airports need equipment to be able to lift wheelchairs in and out of the airplane easily without damage. There also needs to be someone able to communicate with the passenger and coordinate the care the passenger needs. This staff person would be responsible for making sure the wheelchair gets on the plane, make sure there are people capable of lifting the passenger, and that the passenger is helped from gate to gate.”

## KENTUCKY



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### ANNAH (BOWLING GREEN, KY)

“I have traveled by air about 5 times in the last 15 years. I can’t risk it anymore because I am not medically stable out of my chair and my chair is almost always damaged in flight under the plane. On one trip, my chair was damaged to the point I couldn’t function in it. It was not able to go up or down or recline which I use to breathe right. It was not able to drive far without needing a break. I was in pain for 8 months while it underwent repair.”

### JENNIFER (BOWLING GREEN, KY)

“I travel for work about once a year and every 3 years to the SMA conference. On one flight, the gate attendant was very responsive and the guy that loaded my wheelchair came to talk to me beforehand. The result: my wheelchair had no damage. On another occasion, my joystick was broken. It could still be driven but had to sit in my lap.”

### JORDAN (LOUISVILLE, KY)

“We travel to West Palm Beach, FL for my daughter’s specific treatments and regular checkups. We drive instead of flying due to all the equipment she has and her age (23 months). In the future, our daughter (who has SMA) will likely need a wheelchair or mobilized power unit. Not being able to roll onto the aircraft would make us choose not to fly but drive.”

## LOUISIANA



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### SHAUNTAE (DENHAM SPRINGS, LA)

“People with SMA and others with physical disabilities who travel by air must check their wheelchair with no confidence or assurance that their lifeline to independence and mobility will arrive undamaged. Let’s ensure policies and laws in making traveling accessible for all so that we can have our pursuit of happiness.”

### CYNTHIA (MONROE, LA)

“I have a relative who recently got theirs damaged. Something needs to be done.”

### LESLIE (RUSTON, LA)

“As a physical therapist, I work with many individuals who use a manual or power chair for mobility. These chairs are an extension of their bodies, just like your legs are for you. Can you imagine being asked to ‘check’ your legs to board an airplane? Probably not. I feel any wheelchair with adequate transport hardware should be allowed in the passenger area of the plane with its owner seated in it, just as they would to ride in any other public transportation.”

### TIFFANY (STERLINGTON, LA)

“Asking a person with SMA to check their wheelchair is essentially cutting off their legs and asking them to continue walking without assistance. We need to find a better way to make sure air travel is more accessible for everyone.”

### ALYSSA (YOUNGSVILLE, LA)

“I’d fly MUCH more often if I could roll my wheelchair onto the aircraft. Sitting in airplane chairs is a huge struggle for me due to lack of support with my abnormal shape. I have lots of pain when sitting in airline seats. Using my wheelchair on the flight would allow me to fly with one companion instead of multiple, which I need now for transfers and adjustments. Poor handling of my wheelchair on one of my trips caused footrests and protective battery coverings to break, which took weeks to get the airline to cover repairs for.”

## MAINE



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Cure SMA estimates that there are approximately 37 people with SMA who live in Maine. However, we did not receive permission to publish their air travel experiences for this report.

## MARYLAND



### MICHAELA (ANNAPOLIS, MD)

“My own specialized wheelchair (worth \$30,000) is broken almost every time I fly. A hooyer lift is the safest way for me to transfer seats, but one is never available when transferring to an airplane seat. In addition, I am unable to use the bathroom on any plane because there is no hooyer lift, nor room to maneuver it.”

### DEREK (MOUNT AIRY, MD)

“My son with SMA attends college out of state. We anticipate he will be traveling by air 5-7 times per year. Air travel is the only option due to the distance between home and school. The airline has treated his wheelchair with great care, and we have not had any issues with damage. However, we do anticipate that using the restroom will be a challenge for my son. With inaccessible bathrooms and no mobility device on board, there are very limited options for restroom use.”

## MASSACHUSETTS



### MIKE (SEVERN, MD)

“I never travel by air, which we would do, but for the risk of damaging my power wheelchair. The treatment of a very expensive AND necessary piece of equipment like luggage is unacceptable. Having the airline willing to pay for damages doesn’t offset my inability to actually do ANYTHING at my travel destination without my power chair.”

### OWEN (BRAINTREE, MA)

“I choose not to travel by air and will instead drive very long distances because I have absolutely zero faith my chair will be put on the plane with me. One time, I flew from Boston to Detroit to Fort Wayne and my chair was left in Detroit for the next day until they could drive it down to Indiana.”

### CAROLYN (CAMBRIDGE, MA)

“Luckily, I have never had an experience (yet) that went catastrophically wrong. I’ve had minor - moderate chair damage or delays, service dog delays, being rushed at boarding or having the chair take a long time to be returned but compared to what others have endured I feel lucky.”

### DANIEL (HAYDENVILLE, MA)

“We fly once every year or two. Every time we have flown our wheelchair has arrived undamaged and the gate attendant and staff have always been very helpful. The biggest issue is the inability to use the bathroom on the flights. I am forced to eat and drink as little as possible before and during the flight because I am unable to get to the bathroom during the flight.”

### MARY (HAYDENVILLE, MA)

“We travel at least once a year and I hold my breath from the time our son gives up his power wheelchair at the gate until it’s returned to us in one piece. So far, we have been lucky with airline staff. We do plan ahead, calling the airline to tell them our needs and giving them info on the chair.”

### NICHOLAS (NORTH CHELMSFORD, MA)

“I travel by air very infrequently (once every few years) because of the high likelihood of injury and damage to my medical equipment. On past flights, I was not given enough time to reach my seat before others began to board. I witnessed my wheelchair fall off the baggage ramp. When I arrived, my chair’s motor was damaged and needed repair. I spent the first two days of my trip waiting for it to be fixed, unable to leave the hotel. I would fly at least once a year if wheelchairs were allowed in the cabin of the airplane. I would have much less dependence on care attendants and airport employees who are ill-equipped to handle sensitive medical equipment.”

## MICHIGAN



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### ELIZABETH (CANTON, MI)

“We prefer to drive when we can. My daughter’s wheelchair usually is returned with minor cosmetic damage but twice, it was damaged so badly it needed repairs. She also experiences significant back and leg pain during and after flights due to the lack of support in the plane seats. On one flight, my daughter was seated in the very last row and was left with bruises on her thighs after being thumped through the entire length of the plane in an aisle chair.”

### TAMMIE (LIVONIA, MI)

“I have not traveled on a plane in 25 years due to my motorized wheelchair always getting damaged when being stored beneath the plane. Parts have been snapped off making it unusable and therefore making my vacation a disaster. Imagine boarding a plane just fine and then when you arrived at your destination someone broke your legs. Not only would that ruin your trip but also make your everyday life difficult. In addition, I am not sure how I would transfer anymore since I have become weaker. A good air travel experience would be not having my chair damaged and being able to sit in my power chair on the plane since my chair is painstakingly fitted to my body’s needs.”

### CATHY (VAN BUREN TOWNSHIP, MI)

“My daughter has SMA Type 2. She travels with me or a close friend by air at least 3 times a year and up to 6 times per year. We are too nervous to bring her Quantum power chair to the airport and allow them to transport it. There is too much risk of it getting damaged and then she would have nothing. So, we purchased a foldable power chair for our travels by air. We bring the chair to the gate, and I carry her onto the plane. After she is seated, I walk back off the plane to fold up her chair and secure it in a bag. Our method has worked well for over 15 years.”

## MINNESOTA



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### CASSIE (BELLE PLAINE, MN)

“We do not travel often as the seats are not comfortable for my son who has a spinal fusion and needs stability for safety. Also, because the risk is too high for damage to his powerchair. We have experienced broken powerchair joysticks in the past.”

### ADRIENNE (MINNEAPOLIS, MN)

“I wish I could travel more than I do— 1 or 2 times every couple years— but it’s too nerve-racking thinking about my chair being damaged or having to think about the emotional stress of traveling with a disability. I rarely feel like I’m respected by the airline staff/TSA and it’s glaringly obvious that I’m a second-class citizen. It’s humiliating.”

### AMANDA (MINNEAPOLIS, MN)

“We have been fearful of flying with our son with SMA due to the damage that has been imposed on power wheelchairs. Airlines should not be allowed to pay their way out of these situations when someone’s livelihood is at stake.”

### TAYLER (NORTH BRANCH, MN)

“I haven’t traveled by air since 2012 because the accessibility is not available and it’s hard to transfer me to airplane seat and I don’t have great body control out of my wheelchair. It would be nice to travel in my own wheelchair without having to deal with transferring into a chair on the plane. My wheelchair is designed to fit my body and keep me upright, unlike an airplane seat.”

### ALY (SAINT PAUL, MN)

“I travel by air a few times a year, but only when I’m able to bring a PCA as it’s impossible to travel on a plane alone. The best times traveling by air have been when we’ve encountered good people. Transferring to the aisle chair is always an anxious experience. Last time I traveled, the gate attendant was so kind and let us go in a more private area. Other times have not gone as well. I’ve seen my chair fall down a flight of stairs on the tarmac because they insisted on lifting it instead of pushing it to an elevator. What airlines do not understand is that a voucher to fix the chair does not help with the current situation. Our chairs are our lifeline and too often have my trips, or life back at home been impacted for weeks because of a non-functioning chair.”

### SUSAN (SAINT PAUL, MN)

“I haven’t flown because of current airline policies of having to transfer to an airplane seat and check my power chair as baggage. Allowing wheelchairs on the airplane would mean that I could finally take trips to far away locales for business or vacation.”

## MISSISSIPPI

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Cure SMA estimates that there are approximately 113 people with SMA who live in Mississippi. However, we did not receive permission to publish their air travel experiences for this report.

## MISSOURI

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### JOY (BROOKLINE, MO)

“We choose not to travel by air with my grandson with SMA (age 4) because the logistics of transporting his power chair, cough assist machine, ventilator, etc. is just too complicated. The ability to fly in his own power chair would help. The tie-down system used in accessible vehicles would be all that is needed to make flying with your chair possible, as most people in power chairs have seatbelts/restraints built into their chairs. If theme parks can use these types of things, surely airlines could figure it out.”

### JESSI (KANSAS CITY, MO)

“After one flight, the arm rest on my chair wouldn’t unlatch so it could be lifted up and out of my way to transfer. So, I couldn’t get out of the chair by myself. Luckily it was my old, spare chair. Another time the brakes somehow got messed up on one side so I only had one brake until I got to the hotel where it could be fixed because we brought tools with us just in case. Again, it was an old chair because I will not travel with my current chair as I don’t trust the airlines.”



### LYNETTE (NIXA, MO)

“We live 1,000 miles from family and try to visit once a year. We usually drive because flying is a big headache. The concerns are number one: a damaged wheelchair; but also, being comfortable on the plane, using a bathroom on the plane. Layovers can be particularly stressful because sometimes they bring the chair to you and sometimes, they don’t. There is always a worry of missing a connection because you’re waiting for your chair. Or a worse scenario is they don’t bring the chair because there is a tight connection.”

### JOY (BROOKLINE, MO)

“We choose not to travel by air with my grandson with SMA (age 4) because the logistics of transporting his power chair, cough assist machine, ventilator, etc. is just too complicated. The ability to fly in his own power chair would help. The tie-down system used in accessible vehicles would be all that is needed to make flying with your chair possible, as most people in power chairs have seatbelts/restraints built into their chairs. If theme parks can use these types of things, surely airlines could figure it out.”

## MONTANA



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Cure SMA estimates that there are approximately 34 people with SMA who live in Montana. However, we did not receive permission to publish their air travel experiences for this report.

## NEBRASKA



### LISA (SYRACUSE, NE)

“It is too difficult to travel with our daughter in a power wheelchair. The worry about having to transfer out of the wheelchair and what happens to the wheelchair during travel. Until they make changes so she can stay in her chair, we would choose not to use air travel.”

## NEVADA



### CECILIA (NORTH LAS VEGAS, NV)

“I have only traveled via plane once in my 31 years of life. I choose not to travel because I am not able to take my lifeline which is my wheelchair. I’m afraid of my wheelchair being damaged, especially far away from home. Insurance sometimes doesn’t want to fix damages or will take a very long time. Our power wheelchairs are built to fit our bodies perfectly and our manual wheelchairs are often not our size. The one time I did fly, my sister carried me on the plane. I have not yet used an aisle chair but can assume getting carried in between seats is hard. I can’t even imagine using the bathroom.”

## NEW HAMPSHIRE

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### ABBY (SALEM, NH)

“There have been many occasions where my wheelchair was damaged or lost during travel. That, or assistive staff injured/hurt me when transferring to the aisle chair. It is always a miracle if my chair does not get damaged and staff that handles assistance is knowledgeable about helping those with mobility issues.”

### MARC (SALEM, NH)

“We travel several times per year during pre-Covid times. Less now. Booking flights with a wheelchair is subject to everyone at the airline communicating correctly. We have had damaged wheelchairs, missing wheelchairs, and wheelchairs put on luggage conveyor belts. We also had to wait all night until the power wheelchair showed up.”

## NEW JERSEY

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### TAMI (MATAWAN, NJ)

“My son can’t get on an airplane because his specialized wheelchair does not fit on a plane. No accessible bathroom also.”

### DANIEL (RUTHERFORD, NJ)

“We have traveled by air twice in our daughter’s 5 years since birth. Even with preboarding for disabilities, it is extremely hard getting everyone and everything onto the plane and getting our daughter into her seat. We even had extra legroom, but the amount of running back and forth to set up the car seat, come back for her equipment, then come back and have to carry her to her seat was a lot of work and hard to do especially as the rest of the boarding commenced. Having the ability to remain in the wheelchair during the flight would be the biggest thing, similar to how buses have wheelchair-dedicated areas where seats fold up and down based on need.”

## NEW MEXICO

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### DESIREE (ALBUQUERQUE, NM)

“I haven’t flown in over 5+ years because I’m afraid the airlines will destroy my chair, which they have done on past flights and were very rude about it. On good air travel experiences, I was the first and last to board the plane and they did not damage my chair. Being able to roll onto the plane with my own wheelchair would make flying way easier and I would fly more frequently.”

### TARA (ALBUQUERQUE, NM)

“Our daughter with SMA has travelled with us around the globe. She loves to travel, and we love to travel with her. She also must travel by plane to see her doctors a couple of times each year. But every year as she gets bigger, getting her in and out of her wheelchair and in and out of a tiny bathroom gets more and more challenging. Her body is extremely weak, and she needs physical supports. Please pass legislation to help ensure every person with a disability has the amazing opportunity to travel - or just the ability to go see their doctors if needed. It shouldn’t be as hard as it is to travel in a wheelchair.”

### PAT (SANTA FE, NM)

“I very rarely travel by air. I prefer to go by car.”

## NEW YORK



### JOE (CHARLTON, NY)

“As a person with SMA who relies on a wheelchair with a customized seating system for mobility and independence, I must check my wheelchair when traveling by air. Doing so is a major gamble as there is no guarantee that my only means of mobility (and basically my only way to sit upright unassisted) will not be damaged. In addition, the process of having to transfer to an airline seat is a major undertaking as I have to be physically lifted and then positioned in the seat using strapping and padding due to my poor muscle tone. This process is very dangerous as it puts me at risk of being dropped or falling out of the airline seat.”

### VICTORIA (DIX HILLS, NY)

“We choose not to travel by air much because my daughter (25) has a custom power chair that cannot be taken apart. We have to travel with a manual wheelchair and leave the custom power chair at home and rent a generic power chair at the destination. On one trip, the aisle chair was not available right away, and our daughter cannot walk. Getting her to the bathroom is also extremely difficult because we have to lift her one and off the toilet and the bathroom barely fits 1 person.”

### ANDREW (NEW YORK, NY)

“On a flight to the Dominican Republic, getting into the plane was fine until I had to be transferred to a seat without an adjustable armrest. This made the transfer very difficult. On the way out of the plane I once again had a very difficult transfer due to the arm rest not being able to go up. When I finally transferred into the aisle chair, I was brought to my manual chair soaked in water and I was very displeased.”

### TARA (STATEN ISLAND, NY)

“Before I was in a wheelchair I would travel by air at least twice a year, unfortunately, since I’ve been in a wheelchair and not able to walk at all I have chosen not to travel by air because of all the horrific stories I have heard about what happens to your electric wheelchair in the cargo section of the plane. I also am very uncomfortable having somebody try to lift me to transfer me to an aisle chair and then into an airplane seat.”

### CRAIG (STILLWATER, NY)

“It is far too difficult to get in and out of the tight seating.”

## NORTH CAROLINA



### KEVIN (CARY, NC)

“I do not travel by air anymore after a terrible flying experience in 2019. The airline broke my power wheelchair once on the way there and twice on the way back. It was a horrendous experience. Allowing me to roll onto the aircraft in my wheelchair would be huge. It would enable me and so many others to travel more freely for work and pleasure.”

### ANDREW (CHARLOTTE, NC)

“My grandson has SMA and as he grows older is facing increased challenges in air travel, some of which is to receive specialized medical care. Air travel for people without disabilities is hard enough but the disabled face a system that generally ignores their unique and special needs.”

### DEBORAH (MOUNT AIRY, NC)

“We don’t travel by air because our son cannot sit in anything other than his power chair. Additionally, we must travel with a lot of medical supplies. I don’t think we would be accommodated. Allowing the wheelchair on the airplane would open up much more travel options for our family.”

### ABBY (RALEIGH, NC)

“There is literally no accommodation for my child in a wheelchair. I have to carry him out of his chair (which I spend the entire flight praying does not get damaged). There is no way he can get in or use the bathroom—we have to go before we fly so we don’t book long flights. The lack of care or understanding from airlines is honestly disturbing as a parent.”

### BETHANY (SOUTHERN PINES, NC)

“I haven’t traveled by air in many years. I choose not to travel by air because of how inconvenient it is since I have SMA. On one trip, the side of my wheelchair was damaged, and the airline denied it.”

## NORTH DAKOTA



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Cure SMA estimates that there are approximately 32 people with SMA who live in North Dakota. However, we did not receive permission to publish their air travel experiences for this report.

## OHIO



### MATTHEW (AVON LAKE, OH)

“We travel by air approximately once per year. We choose not to travel by air for shorter trips because it is not worth the cost or hassle. We fly for trips where it takes too long to drive with our family. We typically only fly on direct routes because connections add risk of damage to our sons’ wheelchairs. We also need extra time for connections, which often is not possible. We have been lucky so far, but each trip puts the wheelchair at risk.”

### RICK (CANFIELD, OH)

“I traveled frequently for business up until 2 years ago. I can no longer use air travel as my power wheelchair is not compatible with current plane configurations. I do not have the strength or mobility to use a standard wheelchair - thus prohibiting travel.”

### DANA (COLUMBUS, OH)

“On one flight, as we were waiting for my wheelchair, my wife witnessed the ground crew tugging my chair on its side to slide it across the runway. By the time we received it, the mud guard had been completely torn off and the control box was badly bent along with other minor issues. Because the chair is so personalized for my needs, I had no opportunity to accept repair right then at the start of my vacation. I had to wait until I got home for repairs to be made.”

### MARIEKE (COLUMBUS, OH)

“I travel several times a year for medical needs and for vacation. On one domestic flight, I experienced unfriendly gate personnel and no help with boarding to delayed wheelchair assistance (making me almost miss my connection) and parts of my wheelchair were bent (thankfully not broken).”

### ROCHELLE (COLUMBUS, OH)

“Prior to COVID, I flew 2 to 3 times per year domestically. Most of my trips were for leisure, although some were for work. The worst experience I had involved a broken arm. Due to airline policy, I had to be transferred from my wheelchair to the aisle chair by airport staff versus my family member that was with me. There were miscommunications, and my arm broke as a result. I have also had serious damage to my power wheelchair when flying.”

### MADISON (DUBLIN, OH)

“I have never traveled by air because I need to recline and can’t sit up in any seat. Being carried and transferring to a seat would be very risky and there is limited space for the equipment I need with me like my ventilation, suction, and feeding pump. I would try flying if I could roll on in and stay in my chair.”

## OKLAHOMA

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### ALLIE (STILLWATER, OK)

“On one flight, I was stuck on the gate/tarmac in Las Vegas because of rain. Everyone else on the plane was allowed to deplane and relax outside the gate and eat and use the bathroom. The pilot told me I could get off, but they would have to unload the plane and reload it when given the clearance and it would delay us more. I chose to stay on the plane to not delay more. We had an 8-hour delay on what was supposed to be a 3-hour flight. The whole time I was stuck on the plane without my custom seating, and I could not use the bathroom. It was hard and I ended up getting a pressure sore and had other health problems from that trip.”

## OREGON

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### KELLY (MOLALLA, OR)

“I travel once or twice a year for vacations. On one positive flight, I was allowed to board first, drive my chair into the plane, up to the seat and then my husband can do a direct transfer from wheelchair to airplane seat and vice versa upon arrival. When I have to use the aisle seat, it is always harder. It causes me more bodily pain and I always feel very unstable, and it takes a lot of strength to hold myself upright as I am being pushed up and down the aisle.”

### WREN (PORTLAND, OR)

“I needed help using the accessible bathroom on the plane. My parents always have to carry me. It was almost impossible to fit two people in without getting hurt. I got hit on the walls, multiple times.”

# PENNSYLVANIA

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## LISA (EAST STROUDSBURG, PA)

“If I could roll onto the aircraft, I wouldn’t need help transferring to an aisle chair when sitting and getting off the plane. I would be able to fly independently.”

## ELIZABETH (HAZLE TOWNSHIP, PA)

“I have never flown because I am too afraid my electric wheelchair (my only way of getting around) will get damaged.”

## ABBY (IRWIN, PA)

“I love to travel, and I have been very hesitant to fly for the simple reason that I do not trust airlines to handle my wheelchair. On one flight, the airline didn’t know if my chair could fit on the plane as they did not have a lift from the floor to the belly of the plane. Three or four maintenance people came up to look at my chair to see if they could lift my 500-pound chair. They said they could, but I had to be taken out of the chair immediately to give them extra time. When I landed, my chair was tilted back, and my controller had been moved meaning they did not follow my detailed instructions.”

## NICHOLE (MECHANICSBURG, PA)

“I used to travel by air about twice a year for vacation. I now would rather take multiple days to drive to my destination because of the horror stories of what is happening to wheelchairs more and more often. On one flight, my seat was further back in the plane and the aisle chair didn’t fit with me on it to get off the plane so they tried to just carry me but my legs were being dragged causing a knee injury. Eventually after being made to feel like a complete burden, they put me back in the aisle chair. My elbows and shoulders kept hitting every seat and causing me a lot of pain.”

## DAVID (NEW FLORENCE, PA)

“The biggest concern we have is damage to the chair. Another concern is comfortable and supportive seating in the absence of the chair. Bringing the chair into the cabin alleviates both concerns. The chair is my daughter’s ‘legs’. It’s inappropriate to ask someone to get rid of their legs so they can fly on a plane.”

## KATHLEEN (PITTSBURGH, PA)

“We have traveled with our granddaughter who has SMA. She has a lot of equipment, including a power chair, and we are concerned that items will get lost and/or damaged.”

## NICOLE (WILLIAMSPORT, PA)

“Training all airline employees on proper handling of wheelchairs and disability awareness would help improve the air travel experience for people with disabilities. We had a good experience on a flight from Baltimore to Los Angeles where the airline allowed my daughter to stay in her chair all the way up to the gate of the airplane. She was then transferred into the aisle chair and her chair was taken to the baggage area and loaded onto the plane. I was allowed to have help transferring her and preparing her chair by removing all easily broken or bent pieces and wrapping the chair in plastic wrap. TSA agents were helpful and didn’t expect her to get out of her chair. One challenge we experienced on a different flight was being stuck on the airplane waiting for her chair to be returned to the gate. We were the first on and last off and unable to use the restroom during the flight due to inaccessible restrooms.”

## PUERTO RICO



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### KEISHLA (CAROLINA, PR)

“I usually travel to visit family or vacation, but I have also traveled for medical reasons. I would recommend that airlines allow family or caregivers to help you to get in the airplane; kind of a special pass to help you with transfers and luggage.”

## RHODE ISLAND



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### LYNN (CUMBERLAND, RI)

“It would be so nice to have access to an onboard accessible bathroom for our son with SMA. My husband or I would need to help our son use an accessible airplane bathroom. So, it needs to be big enough and hopefully big enough for his power wheelchair to recline. And if my son could stay in his power chair on the plane, that would be great.”

### STEPHEN (CUMBERLAND, RI)

“I travel 1-3 times per year for vacation and the SMA Conference. On positive trips, the airline allowed us on first, took care to assist our transfer to the seat, and handled my son’s power chair carefully. On another flight, the agents did not listen to me on how to move the power chair manually and how to lock and unlock the brakes. Upon arrival in Dallas, I had to go on the tarmac, in 100+ degree heat to unlock the chair so it could be returned to my son. This took over an hour, and in the interim, he could not go to the bathroom as he would not fit on the changing table due to his size. Upon return home, the wheelchair had to be repaired due to the broken brake lock release.”

## SOUTH CAROLINA



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### MICHAELANGELO (GREENVILLE, SC)

“Because of the inconvenience, risk, horror stories we have seen with other disabled or special needs passengers, we choose not to travel by air unless completely necessary which is about once per year. My daughter needs her chair at all times.”

### KATHRYN (SIX MILE, SC)

“Whenever I travel, I always drive instead of traveling by air because our wheelchairs have to be stored with luggage. The end result is a broken wheelchair, 9 times out of 10. Our wheelchair is our legs, our life. If it gets damaged or completely broken, we have no way to get around once we reach our destination. It would be like taking a passenger, breaking their legs while in the air, and then expecting them to walk when you land. I can’t take the risk of my wheelchair getting broken.”

## SOUTH DAKOTA



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Cure SMA estimates that there are approximately 35 people with SMA who live in South Dakota. However, we did not receive permission to publish their air travel experiences for this report.

## TENNESSEE

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### SARAH (KNOXVILLE, TN)

“I travel a couple times a year, but I try to avoid it when possible. The stress of sending your wheelchair to the belly of the plane and hoping it reaches my destination and is working is horrible. Let alone the pain I feel from having to sit in the plane seat, and the inability to go to the bathroom without my chair.”

### JULIE (NASHVILLE, TN)

“We travel 12-20 times per year, most often for medical appointments but also for vacations. On one trip, we were allowed to ‘early board’, but they let everyone else come down behind us before we had boarded, and people made rude and unhelpful comments. We felt rushed and that leads to discomfort and accidents...feet being rammed into seats, etc. At the end of the flight, the wheelchair came up completely disassembled and broken yet no one offered to help try to put it back together or offer to bring a courtesy chair. They wanted us off the plane, but my child literally had nowhere to sit (and she cannot stand or walk).”

### SARAH (MEMPHIS, TN)

“I take 4-8 trips per year by plane. I often travel for work, to visit family and friends, and vacation. For most flights I take these days, I travel alone. Damage often happens to my power wheelchair when it is laid on its side in the cargo hold. Although I have signs stating this cannot happen, if the door is shorter than my chair, this is often the crew’s solution. In addition to chair damage, I have also been physically hurt during transfers off the airplane and back into my wheelchair. I have had staff tell me they have never done a lift before, and I have even been dropped. The space between the seats often makes transferring off the plane very difficult and dangerous. I always expect to leave a flight with bruises on my arms and legs or in tears.”

### HAILEY (PORTLAND, TN)

“We don’t travel by air because it is not equipped to handle our daughter and her power chair. We flew once with our daughter, but I didn’t like that all her medical equipment couldn’t be with us.”

### SARA (WHITE HOUSE, TN)

“The airlines often break and/or lose wheelchairs leading to not being able to enjoy your trip as you normally would.”

## TEXAS

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### NANCY (AUSTIN, TX)

“I’ve experienced the humiliation of being boarded by the airlines, lifted from my chair, strapped into a dolly of sorts, only as wide as the aisle, painfully lifted from the dolly to the first bulkhead seat. Lifting me from the dolly, over the armrest, and into the seat was a painful chore for all. The crew had to lift me from under my arms, up and over the headrest of the seat which held a higher area for me to be plopped down into my seat. My arms flew out from the grasps and my elbows and shoulders twisted. Once I landed in the seat, they placed the seatbelt on me and scurried off the plane. There I sat, a hurting, disheveled mess ready for take-off. My wheelchair, cushion, and backpack were a different matter as my chair was taken away to be loaded in the luggage cargo bin. And that is one example of one leg of a trip.”



### **MHELLE (BENBROOK, TX)**

“Air travel is a nightmare. The absolute worst experience of ableism from airline and airport staff. One time, my chair was dropped as it came off the luggage belt out of the plane and the wheel broke, the armrest flew off, and the joystick was damaged. Also, I was dropped as staff moved me from my wheelchair to the aisle chair. In this incident, my leg was fractured.”

### **BRIANNA (DALLAS, TX)**

“I travel 1-2 times per year by air currently. However, my hope is to travel even more in the near future and make it a more regular occurrence. My reason for not being able to do this as often as I would like currently is because of the huge burden associated with flying for me. In its current state, flying takes away all of the independence that I am used to having in my day-to-day life and requires me to have to make significant financial, emotional, and physical sacrifices, such as my sense of safety and comfort.”

### **GUS (DALLAS, TX)**

“I travel roughly 3-4 times a year to visit my daughter. On rare occasions, I will travel for work purposes. I once had my scooter damaged by the airline which required the airline to have it repaired. It was mostly cosmetic damage, but it was still a hassle to work out with the service tech to get the repairs done. It was also fortunate that the damage was on the final leg of the trip and not at the beginning.”

### **JULIA (DALLAS, TX)**

“We travel 2-3 times per year. On one positive experience, we received medical pre-board, giving us time to get settled. In addition, the captain and attendants removed their luggage from the captain’s closet to make room for as many wheelchair parts as we could fit.”

### **OLIVIA (FLINT, TX)**

“I used to travel by air 2-3 times a year, but after damage to my manual and power wheelchairs I stopped flying. The airlines don’t care about mobility equipment and small airports refuse to train their employees on proper handling. I was told by one small airport that they only had one employee who was trained to operate equipment to lift my power wheelchair onto the plane.”

### **BRITTANY (GARLAND, TX)**

“I travel every couple of months. Usually, everything runs smoothly with only regular wear & tear on my chair. More training and education for crew, including ramp employees and gate agents, would help.”

### **MICHAEL (IRVING, TX)**

“I choose not to travel by airliner because the last time that I flew, they did nearly \$6000 worth of damage to my wheelchair. Both motors and my hand controller had to be replaced because they used my wheelchair to stack suitcases on in the luggage compartment in the belly of the plane, and the weight of all of the luggage cracked the frame around my motors, and also damaged the motors themselves. There was also luggage stacked on top of my hand controller which damaged it beyond repair.”

### **MARK (STEPHENVILLE, TX)**

“I seldom fly but, if I were able to roll onto the aircraft, I would be on the plane now if that was an option! On one flight, they lost the key to my scooter.”

## UTAH

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### MEGAN (KAYSVILLE, UT)

“My child has no muscle to sit by themselves, even needs support for his head. No airline seat would give him that support, and car seats for bigger kids become unusable. Wheelchairs are the only safe option for my child to protect his body from harm. Understanding from airlines and their staff, showing patience would be helpful. If they don’t allow the wheelchair on the plane, there needs to be a better way to load it. Lifting it with 3 people and throwing it on the belt is not ok. These chairs are expensive, and some take months to get repaired.”

### LAURA (OREM, UT)

“I travel by air about four times per year, mainly for business. I avoid it to an extent because I don’t want my wheelchair damaged and it’s difficult for me to sit in a chair other than my wheelchair for an extended time. The straps on a regular airline seat are not sufficient for me and I’ve been almost thrown out of my seat by landing deceleration. I also had my wheelchair armrest twisted really badly.”

### SHERENE (OREM, UT)

“I used to travel by air frequently for my job. In fact, I flew multiple times a year for business. I even traveled internationally. As my disability has worsened and due to the many problems I experienced EVERY time I flew, I have stopped flying. Which is of great sadness to me as flying was a great love of mine.”

### MELISSA (PROVO, UT)

“I haven’t flown in years. It’s a nightmare. I worry about my own health as well as damage to my chair. One time, they dropped me while strapped into the aisle chair. They continued to load other passengers and stated, ‘they’d get me up in a minute’ while they waited for more help to arrive.”

## VERMONT

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### SILVIA (BENNINGTON, VT)

“The traveling process is very stressful. Everything must be very well planned, from ensuring that I get easy to access seats up to planning for extra time between flights. Even if I am a power chair user, I have to travel in my manual wheelchair because I am afraid that my chair is going to be broken during the flight. On one of my flights, I had to wait extra time because my chair was lost. The only time when I dared to travel with my power chair, by the time of landing, the batteries were damaged. If I were able to fly in my manual or even power wheelchair, my flying experience would be much improved. I would be much more comfortable in my chair, I would feel much safer skipping the transfers between the wheelchair and airplane seat, and I would have the confidence of my chair is safe with me.”

## VIRGINIA

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### KYLE (ASHBURN, VA)

“I have not traveled by air in more than twenty years because of the high risk of damage to my power wheelchair. I would love to travel by air - I live 400 miles from my hometown and would visit more often if flying was feasible - but my chair is highly specialized, very fragile, and extremely expensive. The risk of having to go without my chair for any period of time while it is repaired, or even lost, is not worth it to me.”

### PENNIE (FORT BELVOIR, VA)

“We had a positive experience on a flight to Barcelona, Spain. The airline placed our girls’ power chairs in a “cage”. They were tied down and secured in a metal container. We knew nothing would go wrong and no damage could be done. One of the pilots shared pictures and video with me of this cage being put on the plane before takeoff. Usually, the baggage crew struggles to lift the power chairs onto the plane’s storage compartment. We have learned to take off anything that can be taken off, so it isn’t torn off or damaged. Being able to use their own power chairs on the plane would provide comfort for my girls during the flight. Their seating is custom designed to fit their body. The piece of mind knowing that their chair is okay would be huge.”

### RHONDA (LYNCHBURG, VA)

“The reason I don’t fly is because I do not want my wheelchair to get broken. I would definitely fly if I could remain in my wheelchair. I have a chest strap that supports my balance and also the cushion in my wheelchair is very comfortable for me.”

### JENNIFER (VIRGINIA BEACH, VA)

“Our 6-year-old son has SMA and is completely dependent on others for all his needs. His recent Make-A-Wish trip to Disney World began with excellent gate and flight attendants who were on the initial flight. But after that initial part, the trip fell woefully short of meeting our family’s needs. The problems included a damaged wheelchair, with missing nuts and bolts on the wheels (which made the chair wobbly) and significant delay due to an airplane problem that resulted in our son going 12 hours without food and missing an entire day at Disney World.”

## WASHINGTON

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### THOMAS (BAINBRIDGE ISLAND, WA)

“We travel about twice a year. Our best experiences are when there are no issues with checking the wheelchair or electric scooter at the aircraft door. If there are steps, there is a lift vehicle available. The wheelchair or scooter is provided at the aircraft door at completion of trip.”

### EILENE (KIRKLAND, WA)

“Our granddaughter with SMA lives in the state of Washington. At 10 it is too difficult to travel by air. There is no way to have access directly onto the plane with her chair. Airline seats are horribly uncomfortable for most people, let alone someone with this disability. While other forms of transportation...by sea, by rail and even by bus/car, have made accommodations so much more comfortable and appealing to travelers, the airline industry has reduced service and comfort beyond reason.”

### STEVEN (KIRKLAND, WA)

“A part of our daughter’s chair broke and it wasn’t something they could fix at the airport. These chairs are custom-fitted and are the only means of transport we have! Our daughter can’t sit in a regular seat due to lack of support, not to mention our inability to lift her without the use of a mechanical lift. Airline seats do not support her or allow her to tilt to alleviate pressure. We have had to stop visiting friends and family and cannot go on fun vacations that aren’t within relatively easy driving distance anymore.”

### KRIS (LYNNWOOD, WA)

“On one trip, upon arrival at our destination, my wheelchair chair wouldn’t turn on and nothing worked because my wheelchair had been laid on its side in the plane, and it ruined the power-cord. It was a holiday weekend, so nobody could fix it till I got back. It ruined my entire vacation.”

### SABINA (LYNNWOOD, WA)

“We have a child with SMA Type 1. We choose not to travel because it is difficult for families like ours who have tons of medical equipment and no accommodations on the airplanes.”

### COLBY (PACIFIC, WA)

“I try to avoid air travel as much as possible because my wheelchair has been returned broken to me more than once. Also, sitting in another seat other than my chair is very uncomfortable.”

### MATTHEW (SEATTLE, WA)

“I no longer travel by air. The options for boarding the plane are limited and awkward or embarrassing. My mobility is already very restricted, so the generic seating makes it so I’m unable to move without assistance for the duration of the flight. Sitting in a chair other than my wheelchair for more than an hour becomes extremely uncomfortable. Every single time I have flown my wheelchair was damaged.”

## WEST VIRGINIA



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Cure SMA estimates that there are approximately 55 people with SMA who live in West Virginia. However, we did not receive permission to publish their air travel experiences for this report.

## WISCONSIN



### DONNA (FRANKLIN, WI)

“If I could remain in my wheelchair, I would travel more often. I have muscular dystrophy and have poor balance and weakness issues. The aisle chair never goes smoothly. Transfers are always disastrous. I have been dropped, had my wheelchair broken several times, and frustrated beyond belief.”

### LEAH (FRIENDSHIP, WI)

“On a return flight, our daughter’s wheelchair was supposed to be gate checked so we could use it in the airport during our layover. The wheelchair was not at the gate, and we were told there was a mistake, and it would be at our final destination. We were given an oversized adult wheelchair without straps or belts when we asked for assistance to get to our next gate. It was very cumbersome and unsafe for our daughter. When we arrived at our final destination, the wheelchair was not there. Because it was late at night, there were no employees to help. One employee arrived after we waited for over 45 minutes. He could not locate the wheelchair at the airport and when he looked it up, he told us it had been mistagged and that no one knew where it was. It took 3 days for the airlines to locate the wheelchair and they never told us where it had been.”

### DANY (GREENDALE, WI)

“My children (both affected by SMA) travel by air, on average, once every couple years. When possible, we choose to drive around the United States to destinations because we do not want to run the risk of their wheelchairs being damaged while traveling.”

### BRIAN (HUDSON, WI)

“I travel by air 3 or 4 times a year. I would definitely fly more if there were assurances that my wheelchair would not be damaged and that the entire process of boarding and onboarding was more comfortable. The process usually breaks down on any flight with a connection and my wheelchair is either not handled properly or is actually lost temporarily. Lift assist is usually not ready or available and the aisle chair may not be available either.”

### JENNEL (OSHKOSH, WI)

“I flew once and they had to take my electric wheelchair apart and almost left part of it in a different location when we had a layover in a different state.”

### ATLANTA (STURGEON BAY, WI)

“I don’t travel by air because my child’s appointments are only 2.5 hours away.”

### JUDY (SUSSEX, WI)

“Today I drive more often because I don’t want my \$80K wheelchair to be damaged by handlers who don’t care or have no clue what they are doing. I put signs on the front and back of my chair, detailed with ‘do this’ and ‘don’t do this.’ I assume the people handling my chair will actually read them. My picture is included too, so handlers will know I’m a real person and they are taking care of my legs.”

## WYOMING



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### AMBER (CHEYENNE, WY)

“My wheelchair is like my legs; it is an extension of my body. Sending my wheelchair into the cargo bay of the plane is a gut-wrenching experience. I feel like I roll the dice every time, not knowing what condition my chair will be in when I land. If it was damaged on the flight, then I am literally stranded without any ability to move. My wheelchair has never been damaged beyond use, like many of my friends have experienced, but I want to share just how terrifying it is to even dare to send my wheelchair onto the plane. The ability to roll onto an aircraft in my wheelchair would be truly life changing.”

# ADVOCATE FOR INDIVIDUALS WITH SPINAL MUSCULAR ATROPHY AND THEIR FAMILIES



Cure SMA Advocacy | 800-886-1762 | [advocacy@cureSMA.org](mailto:advocacy@cureSMA.org) | [cureSMA.org](http://cureSMA.org)

*Cure SMA* is a national organization that advocates for individuals with spinal muscular atrophy, a progressive neurodegenerative disease that robs people of physical strength, taking away their ability to walk, swallow, and breathe.