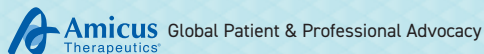


Amicus Patient & Professional Advocacy— empowering those who live with rare diseases

Amicus Therapeutics is dedicated to people living with rare metabolic diseases.

Amicus Patient & Professional Advocacy (P&PA) was created to help improve the lives of people affected by rare diseases—through listening to patients and their communities and partnering with them. Our aim is to support and connect all those touched by a rare disease. From patients to caregivers, advocacy organizations to health-care professionals—we want to work together to achieve common goals. That kind of teamwork may be rare. But it's not rare here. Because this is the *Community of Us*.



Please discuss any medical questions with a health-care professional (HCP).

If you would like to provide feedback on this educational resource or would like additional information please contact:

patientadvocacy@amicusrx.com.

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TRAVEL YOUR WAY PASSPORT



Travel Information and Resources
for People with Disabilities

Emergency Contacts

Please fill in below:

Contact #1

Name _____

Relationship _____

Phone _____

Email _____

Contact #2

Name _____

Relationship _____

Phone _____

Email _____

Contact #3

Name _____

Relationship _____

Phone _____

Email _____



TRAVEL YOUR WAY

Traveling can have its challenges, but with a little planning, organization, and assistance, those challenges do not have to become obstacles.

This travel brochure is designed to help you prepare for your journey from takeoff to touchdown. It is full of suggestions, tips, lists, and resources to help you navigate your travel.

ADVANCE PLANNING

Planning ahead for your trip will help ensure a smooth journey. That includes expecting the unexpected and anticipating potential snags before you set off. The more time you spend getting organized before you go, the more time you will have to relax and enjoy.

Here are some areas where advance planning can really pay off.



Medical

- Make sure you have the following information and documents with you if needed:
 - Healthcare provider's contact information
 - A letter from your doctor approving your travel and any necessary accommodations
 - Background information on your specific disease for those who don't know
 - Lists of all medications, dosages, and prescriptions
 - Make sure all medications are always kept in their original containers with your name on the label
 - Treatments and medical equipment (ie, oxygen C-PAP, tube-feeding supplies, etc)
 - Specific instruction for EMT professionals in the case of a medical emergency
- Obtain a medical alert device, such as a bracelet, necklace, or USB drive, and plan to carry it with you at all times

- Fill out the Medical ID on your smart phone and ensure it can be accessed by medical personnel without unlocking your phone should you be unable to communicate during an emergency

(Please find how to add to your cellular phone via <https://support.apple.com/en-us/HT207021> or via <https://www.addictivetips.com/android/how-to-add-and-access-emergency-information-from-the-lock-screen-in-android-7-0/>)

- Compile a list of emergency contacts, just in case (please see inside front cover)

Medical (cont'd)

- Research and locate medical resources at your destination
 - Check with your doctor, patient advocacy organizations, support groups, and websites for recommendations. Local embassies and consulates can also be helpful in your search
 - Anticipate the possibility of a medical emergency in a location that does not have experience with your disease—or where your language may not be spoken. Be sure to have your doctor's letter and medic alert device handy at all times. Try to have pertinent information translated into the language of your travel destination
- Reschedule any medical visits or treatments around your trip, if needed. If you need treatment while you travel, arrange that with your healthcare provider, case manager, etc. well in advance—including insurance coverage for it
- Discuss a plan for extra medication or medical supply needs in case of unexpected travel delays

Logistics

- If you are traveling through different time zones, consult your healthcare provider and plan ahead for how that may affect your sleep and medication schedule
- If you are traveling abroad, make sure your cellphone is set up for your destination (international service)
- Consider getting travel insurance. It may seem pricey, but the cost of a medical emergency without adequate coverage can be much more so. Before you buy, be sure to read the fine print to see if the policy covers:
 - Preexisting conditions
 - Medical care at your destination
 - Medical evacuation
 - Trip cancellation due to illness
- Make sure your medical equipment will work at your destination and you have the right access to power supplies, such as adapters. Do not forget to bring extra battery power for your equipment in case of delays or other travel interruptions

A background map of Europe and the Mediterranean region, showing countries like Spain, France, Germany, Italy, and the UK, along with major cities and bodies of water like the Atlantic Ocean, North Sea, and Mediterranean Sea.

Logistics (cont'd)

- Find out what you will need to do in the event you get separated from your medication or equipment while traveling
- Your healthcare provider or case manager can help you identify a specialist at your location in case you need medical attention
- Research the location of restrooms on your journey and at your destination. Resorts, tourist information centers, online support groups, and smartphone apps can be good resources for that type of information
- If you plan to use public transportation, check on the accessibility of trains, buses, boats, stations, and depots

Accommodations

- Accessibility is probably the most important aspect of selecting your accommodations when you travel. So before you book, check to see that you will have everything you need
 - Examine layouts and photos of accommodations you are considering
 - Can you get a room on the ground floor so you do not have to navigate stairs in case of an emergency?
 - Can you get a room that comfortably accommodates you and a caregiver if needed?
 - Is there a refrigerator to store medications or special foods?
 - Is there enough space to maneuver a walker or wheelchair? Will it fit next to your bed? In the bathroom?
 - Does the bathroom have an accessible walk-in/roll-in shower with grab bars?
 - Is a toilet seat riser available?

A map of Europe and surrounding regions, including parts of North Africa and the Middle East. The map is color-coded by country and includes labels for major cities, bodies of water, and geographical features. Overlaid on the map are two text boxes: one for 'Ground Transport' and one for 'Air Travel'.

Ground Transport

- Make sure your ground transport is fully accessible. Will you need help getting a wheelchair on or off?
- Plan extra time for ground travel

Air Travel

- When booking a flight
 - Contact your airline's disability or medical assistance support for help with arranging your flight
 - Do they offer any discounts for caregivers traveling with you?
- Check to see what the policy for accommodating medical equipment is, such as BiPAP, walker, wheelchair, or scooter in the airport and on the plane
- Are there electrical outlets on the plane? What kind of adapter might they require?
- Can you pre-check your luggage and equipment?
- Is there an accessible bathroom on the plane? Can you find an accessible seat near the bathroom if needed?
- Will you need assistance getting to your seat once inside the plane?

Air Travel (cont'd)

- Study the airports you will be flying in and out of
 - Arrange for wheelchair assistance at the airport if needed. Contact your airline or airport ahead of time for specific information
 - Check to see if there are stairs or an airbridge that will need navigating or special assistance for boarding the aircraft
 - See if you can plug in your medical equipment at the airport. (Chances are you will not be able to, so be sure to bring extra battery power with you)
 - Consider enrolling in an airport club program that gives you access to special airport lounges that can accommodate your needs. These can be expensive but if you travel frequently it may be worthwhile. Day passes are often available; check with the airline if passes can be purchased in advance

• Check In

- Arrive earlier than your airline recommends. It may take extra time to check in medical equipment and go through security screening
- Contact the security organizations of the countries you are traveling through for support, if you require special accommodations for getting through security screening
- Carry your medications with you in a single bag and be prepared to let the security agent know exactly what is in it. Make sure prescription medications are in their original bottles with your name on them

BEFORE YOU HEAD OUT

All packed and ready to go? For peace of mind before your journey, here's a handy 24-hour advance checklist.



Travel plans:

- Final check on:
 - Ground transport
 - Air/train/ship travel
 - Accommodations
- List of places, people, and contact information
- Check in ASAP and print boarding passes
- Leave all your travel itinerary and copies of your travel documents with a family member or close friend

Carry with you:

- Travel documents including:
 - Tickets/boarding passes
 - Passport/ID
 - Travel insurance
 - Medical insurance ID card
- Healthcare provider letter/information
- Medications in original containers with your name
- Medical alert device
- List of emergency contacts—including local medical expert

- Extra batteries/power source/adaptors
- Equipment manual/directions/supplier contact
- List of equipment specifications, including weight, measurements, battery types
- Dry and fully charged BiPAP or other equipment
- Empty container for water you can fill once you get to the airport
- Snacks, because you never know what, where, or when your next meal might be
- A change of clothes and underwear, just in case
- Your phone and charger

Packed to stow:

- Toilet seat riser
- Power and extension cords
- Chargers and adaptors
- Equipment
- Extra medications

WHILE
YOU ARE
THERE

FINAL
ARRIVING
DESTINATION



While you are there

You've arrived! Here are some tips that may be helpful:

- As soon as you arrive, check to make sure your medical equipment has arrived with you. If not, alert your carrier right away. Also, make sure everything is in working order and not damaged during the trip
- Contact your medical expert when you have arrived in case there is a medical emergency
- Plug in your equipment and get everything charged and ready for your adventures
- To help with jet lag, try resting according to the current time zone
- Pace yourself. Make sure you get enough rest—do not wear yourself out!
- Adjust your medication and treatment timing based on the plan discussed with your healthcare provider
- Before you go out and about, save time and energy by planning your route ahead using helpful apps like Google Maps
- If you are traveling alone, leave a copy of your plans for the day in your room or with the front desk in case of emergency
- Consider renting a mobility scooter so you do not overtax yourself getting around
- Carry your medical information with you at all times
- Keep a travel journal. It does not need to be elaborate—just some notes to remind you of where you have been, what you have seen and what you've experienced. You can even record your entries on your cell phone. This can be shared with your healthcare provider during your next medical visit

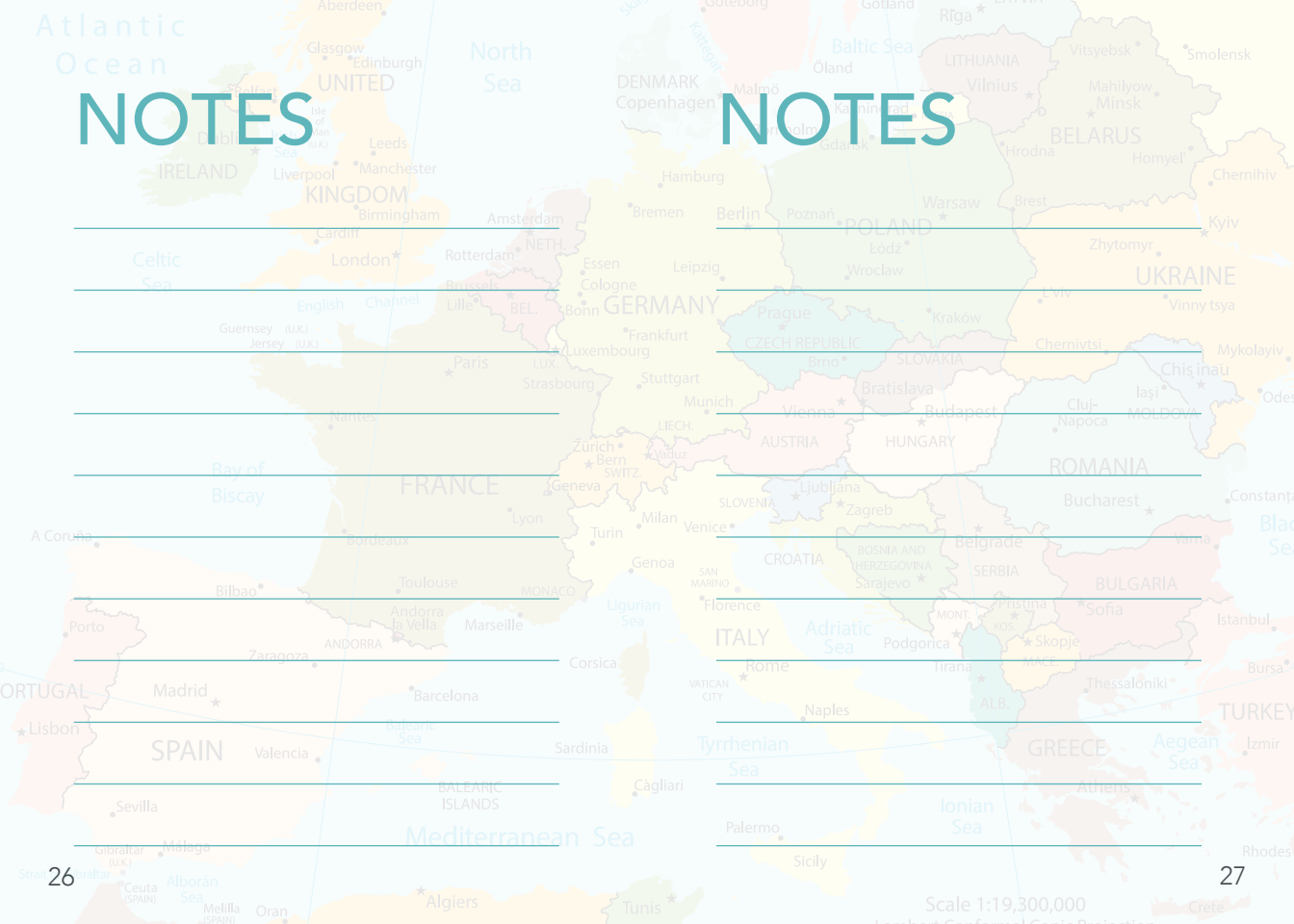
COMING HOME NOTES

Your journey has ended. You had a great time, but it feels good to return to the familiar comfort of your own home. What now?

- Make sure you arrived home with everything you brought with you. Check your equipment to make sure nothing is damaged or missing and notify your carrier as soon as possible if anything is awry
- Decompress. Allow yourself the time and space you need to rest, regroup, and reorient before you jump back into your daily routine
- Check in with your medical team
- Don't let the journey slip away. Put those photos and memories into a scrapbook. Digital ones are easy and great!
- Start planning your next adventure! Add comments to yourself in the notes sections of tips and suggestions you learned on this trip for the next one!

NOTES

NOTES



RESOURCES

Here are some useful resources to help you on your journeys. Your airport website is a valuable resource when needing information and help with ramps, steps, and wheelchair accessibility. Also, local patient organizations can be a valuable resource for help and to answer questions.

ACCESSIBLE TRAVEL

Accessible Travel Forum
(www.accessibletravelforum.com)

Flying With Disability
(www.reducedmobility.eu/20130706333/The-News/flying-with-disability-best-travel-tips.html)

www.heathrow.com/airport-guide/assistance-at-heathrow

www.sagetraveling.com/italy-accessible-travel

AIRPORT SCREENING

Transportation Security Administration:
Disabilities and Medical Conditions
(www.tsa.gov/travel/special-procedures)

Transportation Security Administration:
What Can I Bring? (<https://www.tsa.gov/travel/security-screening/whatcanibring/medical>)

MEDICAL LETTER SAMPLES

International Pompe Association
(www.worldpompe.org/index.php/pompe-disease/patients-helping-patients/274-medical-letter-regarding-pompe-disease-and-your-treatment-in-case-of-traveling)

The Oley Foundation: Sample Travel Letter for Tube and IV Consumers
(<https://oley.org/page/travelletterTubeIV>)

A background map of Europe and the Mediterranean region, showing various countries and cities. The map is color-coded by country and includes labels for major bodies of water like the Atlantic Ocean, North Sea, Baltic Sea, and Mediterranean Sea. Major cities such as London, Paris, Rome, and Athens are marked.

RESOURCES cont'd.

MEDICAL ASSISTANCE WHILE TRAVELING

Getting Health Care Abroad

(<https://wwwnc.cdc.gov/travel/page/getting-health-care-abroad>)

The International Association for Medical Assistance to Travelers (www.imat.org)

Joint Commission International (www.jointcommissioninternational.org)

The International Society of Travel Medicine (www.istm.org)

Travel Health Online (www.tripprep.com)

TRAVELERS BLOGS

M.E.G.'S Confessional

(<https://purplelv93.wordpress.com/category/accessible-travel-2/>)

Jetsetting With Pompe Disease

(<https://nzpompennetwork.weebly.com/travelling-with-pompe.html>)

Curb Free with Cory Lee

(www.curbfreewithcorylee.com)

Friendship Circle

(www.friendshipcircle.org/blog/2012/06/05/air-travelers-with-disabilities-here-are-your-rights/)

PLEASE NOTE: Listing of websites above does not imply endorsement of any products or services by Amicus Patient & Professional Advocacy, just an example of the types of information available as you begin to plan your trip.