

**START HERE**

## About this leaflet

We help you think about the issues which face most McArdle's people while traveling by plane, train, bus or car and while away from home. The suggestions are geared to making travel easier and reducing the risk of an episode of rhabdomyolysis.

### Before you travel

We recommend that before traveling you should have a good understanding of McArdle's, the key management techniques and how to recognize the need for medical attention. See the "Further information" section on the back page.

### Ideas for all degrees affected

There is a very wide spectrum of degrees to which people with McArdle's are affected. We address the issues regarding travel for everyone, from those who travel in a wheelchair through to those who are off on a mountain climbing vacation.

## Information to take with you

It is rare to have an serious episode of rhabdomyolysis, but just in case you have one while you are away:

- Have one of the information/emergency cards in your pocket at all times.
- In your hand luggage have a copy of the "At hospital" leaflet.
- If you have an emergency letter from your McArdle's specialist, take that as well.



## Business travelers

- Explain to traveling colleagues about McArdle's and that you may need to pause for a rest.
- Consider walking to the gate/platform on your own, rather than risk rushing at a colleague's pace.
- The same applies to walking to meetings.
- Maybe send presentation material ahead to your destination hotel, to avoid needing to carry it.

## Other languages

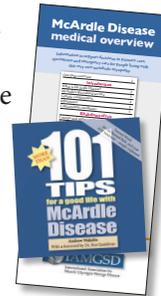
If traveling to a country where English is not the prevalent language:

- Familiarize yourself with the auto translate facility on the IamGSD website (see instructions on the "Languages" button on top of any page).
- If you plan to take a laptop/tablet, configure the auto translate feature in advance of your trip.
- Consider printing out a translation of the "At hospital" leaflet to take with you.

## Further information

A great deal of information and a wide range of leaflets and books are available on our website. Browse on-line or download free PDFs.

Questions? Contact us on: [info@iamgsd.org](mailto:info@iamgsd.org).

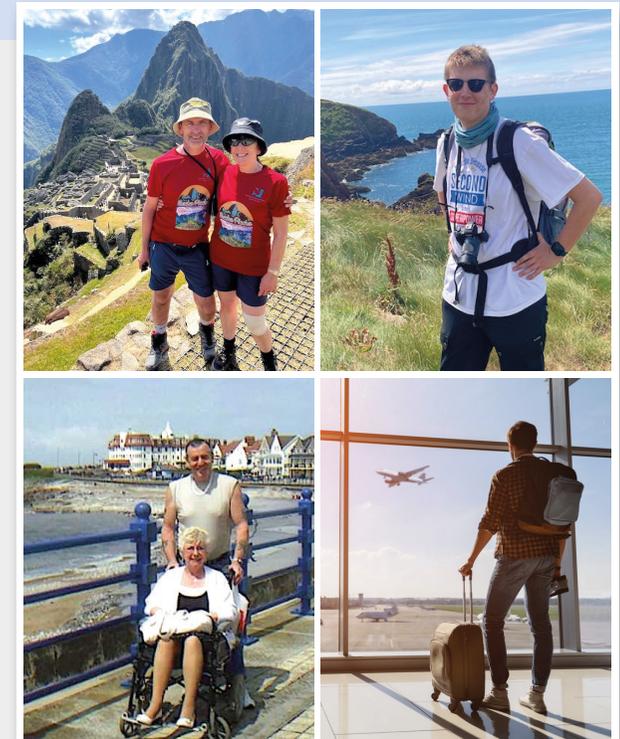


DISCLAIMER: IamGSD uses its best endeavors to provide accurate, factual and up-to-date information on this ultra rare condition. However, each person must take into account their own circumstances, diagnosis, and any additional genetic and medical factors and is advised to consult with their doctor before making use of our generic guidance. Please refer to the disclaimer on the Medical menu of our website.

# Traveling with McArdle's

## Ideas on how to plan safe travel

Most people with McArdle's can travel with little difficulty. But there are things to think about, especially for the worst affected.



Front cover photos

Top left: Deborah (McArdle's) and John Corcoran had an amazing trip to Machu Picchu in Peru, walking 26 miles to an altitude of over 14,000 feet.

Top right: Hans Meißner from Germany on a walking course in the UK.

Bottom left: Margaret Carter (McArdle's) and husband John enjoying a sunny holiday in Wales.

Bottom right: Allowing plenty of time for a flight connection.



International Association for Muscle Glycogen Storage Disease

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## In a group or alone?

- If you can travel in a group whether family, friends or work colleagues, you will have someone to assist you when necessary.
- Or traveling with just one non-McArdle's person can provide reassurance to those worst affected, such as a wheelchair user.
- Even traveling with just one other McArdle's person will at least mean you can help each other.
- If traveling on your own you should be extra careful with your planning.



## Home or abroad?

Much of your preparation will be the same whether you are traveling within your home country or going to another country, but think about:

- Consider the language spoken at your destination and prepare for it (see the "Other languages" section on the back cover).
- Will you know how to call an ambulance or get to hospital? Easy in the hotel, how about in the street?

## Your luggage

- Pack as light as you can.
- A suitcase with four wheels is much easier on the muscles than one with only two wheels, or none.
- Your hand luggage is best in a backpack so that you can carry it on your back, rather than in a hand.
- If using a shoulder bag, try to have one where you can place it on top of your suitcase and slip its strap over the handle.
- If your hand luggage needs to go into an overhead locker or rack, consider asking an attendant or another passenger to lift it for you.



## Airports and stations

- If you struggle with your McArdle's, consider whether you should book assistance at the airport or train/bus station.
- From provision of a wheelchair up to an electric buggy ride to your departure gate.
- Consider whether you also need to book assistance at the arrival airport/station.
- Get to the airport/station early to reduce stress and avoid the potential for having to rush.
- Allow plenty of time to navigate your way through baggage check and security, and get to the gate.
- If you need a connection, try to choose a service which will allow you plenty of time, even if your incoming service is late.



## Planes and trains

- On a long journey, especially in the air-conditioned atmosphere of a plane, beware of dehydration. Avoid alcohol, and drink water.
- After sitting on a journey such as a long-haul flight you may find your muscles feel weak.
- Consider walking up/down the aisle once an hour.
- Take extra care as you get moving again. Whilst seated prepare for standing: e.g. raise heels and toes alternately, and circle ankles several times.
- Wear comfortable/loose clothes for cramped spaces.
- Beware of holding awkward positions in crowded conditions such as on trains and buses.

## Your hotel

- If your hotel is in the city that you travel to, perhaps it has a shuttle bus to collect you from airport/station.
- Best not navigate public transport with luggage.
- If hotel has many floors, consider requesting a room on a lower floor. In event of a fire alarm, elevators may be out of service. Rushing down many floors while tense with panic could be damaging.



## Vacation activities

If you are on vacation there may be all kinds of tempting activities to try. A useful guide is to avoid any activities which you have not previously done back home, in case they provoke an episode of rhabdomyolysis.



People with McArdle's have been caught out by scuba-diving, zip lining, bungee jumping, etc. The risks are not always obvious – e.g. holding an awkward position, being tense with fear or excitement, or scaling a ladder to get back into a boat when tired/cold. Activities that the operator says are easy/safe, may not be so for us.

- Renting an e-bike can be a great way to join in with a group bike tour in city or country.
- Hiring a tour guide for your own family group would be much better than joining a public group.

## Try to avoid dangers

Tourists are often targets for street robberies and other trouble. People with McArdle's have had episodes of rhabdomyolysis from having to run away from trouble, or fight off an attacker.

- Take advice from your hotel reception and tourist information offices about areas to avoid.
- Do not openly display property such as expensive cameras, smart phones and wallets/purses.

## Check your insurance

Check whether your insurance covers you for medical attention. If travel is included in your home policy, or a membership group policy, this cover may be broader than a specific travel policy. Whatever policy you have, check whether you need to declare your McArdle's.

**Remember, whatever else you do,  
relax and have a great time!**