

Travel Fact Sheet – Top Tips for a fun filled holiday abroad



Research

Get advice about travelling abroad, including the latest information on safety and security, entry requirements, vaccinations and travel warnings. [Foreign travel advice - GOV.UK \(www.gov.uk\)](https://www.gov.uk/foreign-travel-advice)

Vaccinations

Make sure all vaccinations are up to date (check at least 8 weeks before travelling). And, if on GCSF, schedule vaccine for when neutrophils are likely to be high.

Local Hospital/Doctors where you'll be staying abroad

Locate the nearest hospital (good for cardiac/paediatrics etc) and note down the Emergency services number to call. If travelling somewhere where you don't speak the language, consider writing out a short description about the person with Barth syndrome and their medical equipment/medication in the language spoken at your destination so that you can show it to airport security/hotel staff etc if needed.

Travel and Medical Insurance

Travel insurance is essential to cover cancellation, repatriation, lost or stolen luggage, or expensive healthcare costs in the country you're visiting. Some of the websites that Barth families have found useful include:

www.payingtoomuch.com

www.allcleartravel.co.uk

www.holidayrisk.com

www.staysure.co.uk

www.medicaltravelcompared.com

When filling in the forms online to get travel insurance quotes you will need to tick the boxes that describe the Barth individual's symptoms as there is no option to choose 'Barth syndrome'. Instead tick 'Dilated cardiomyopathy' and answer the questions that you're asked. Note that ticking a box that says that the person gets breathless when walking a short distance will result in a much higher quote as it indicates full blown heart failure whereas ticking the box that says that the person 'cannot walk far due to another, unrelated medical condition' brings the quotation down and is most often the truth for someone with Barth syndrome.

Add any other symptoms like neutropenia etc. When selecting 'Neutropenia' make sure you state that it's not due to cancer treatment and, if the person is well managed on GCSF etc and does not have many infections, then make sure to note this. Always tell the truth when answering the questions or your insurance may be invalidated in the event of a claim.

GHIC Card

Apply for a GHIC (Global Health Insurance Card) which replaces the EHIC and which give you emergency medical cover if you're holidaying in the EU - <https://www.gov.uk/global-health-insurance-card>.

You can use your card to get state healthcare that cannot reasonably wait until you come back to the UK (sometimes called "medically necessary healthcare"). This includes things like:

- emergency treatment and visits to A&E
- treatment or routine medical care for long-term or pre-existing medical conditions

Please note that a GHIC never covers repatriation (although travel insurance usually does).

Medications & Equipment

- Pack all essential medication in your hand luggage (with spares in suitcase) and make sure that all medications are in their boxes with labels showing patient's name and dosage.
- Take a recent copy of the person's prescription.
- If you have a Hospital Management Plan from the Bristol NHS Barth Syndrome Service, take this, along with a copy of the person's latest clinic letter/s.
- If you travel with a defibrillator, pack this in hand luggage as it contains a lithium battery which often is not allowed in the hold.
- If the person has a reveal device (e.g. Linq) or an internal defibrillator (ICD), make sure that security don't use the wands over the area where it's implanted, takes the device ID card to show security.
- If tube fed, take any feeding equipment and prescriptions. Check whether you can easily buy more formula/feed at your destination or ship in advance to where you will be staying. Advise security that a gastric tube is present.
- If travelling with a Continuous Glucose Monitor, check out what advice is needed. Also, for anyone prone to low blood sugar, take dextrose tablets.
- Take a supply of sick bags if prone to travel sickness.
- If travelling somewhere hot, consider taking clip on fans (or ones that go around your neck), cooling towels and bug repellent as well as antiseptic ointment as many people with Barth syndrome react extremely poorly to bug bites of any kind.
- If travelling with a wheelchair or specialist buggy, make sure the airline knows and that it will be waiting for you at the aircraft door upon arrival and not at baggage retrieval.
- If you need mobility assistance, arrange ahead of travel. This can often be done via 'Manage My Booking' or by contacting the airline. You can then advise them of your specific mobility

requirements as well as arranging for an airport wheelchair or taking your own on board. You need to do this at least 48 hours ahead of your flight.

- Most airports participate in the 'Sunflower' Lanyard Scheme to indicate to staff that you have a hidden disability – request at check in to make movement through the airports easier.
- Pack over the counter pain medication, a basic first aid kit, a change of clothes and favourite snacks in your hand luggage.
- If on GCSF, think about giving a dose a few hours before the flight by adjusting their schedule in the days ahead of the travel if needed. Ask advice from the Bristol Service first.
- If the person often gets ear infections when on holiday, think about getting antibiotic eardrops from their GP to take on holiday or buy over the counter drops to prevent swimmer's ear.
- If the person struggles with pressurisation on the airplane, consider buying [earplugs](#) to reduce discomfort. Chewing gum or having a bottle of formula during take-off and landing can also reduce discomfort.

Banking

Think about notifying your bank that you'll be travelling overseas.

Check for affordable exchange rates and bank charges when using your card overseas. You may want to buy a foreign currency card like Revolut, FairFX etc

And finally.... Relax, kick back and enjoy your holiday!