

FRIEDREICH'S ATAXIA & COVID19

Those with FA should consider themselves as vulnerable and self-isolate

(visit hse.ie for more information)

WHY?

- Friedreich Ataxia (FA) is a fatigue disorder. A FA'ers body is making less ATP (energy) than a person without FA. So, when a sickness hits, they have less energy reserves to fight the sickness.
- Researchers and clinicians say every FA heart is abnormal (even if the FAer has a normal ECHO) due to the striations in the heart muscle, which makes the FA heart less resilient in times of stress. So, in the case of extreme sickness (COVID-19) will that FA heart be strong enough and resilient enough? No one knows.
- Many/most FA'ers have a reduced lung capacity (as a result of FA and kypho-scoliosis). In times of extreme sickness, especially the "flu", lung strength is important.

BE PREPARED

In the event that you become unwell, it would be recommended that an FAer have the following items at hand

- detailed medications list
- hospital bag
- Results of last ECG, Echo and other relevant tests.
- Details of where these tests were done
- FARA in USA has a number of documents on their website <http://www.faparents.org/fapg/Medical/emergencies.cfm> - particularly the document relating to fluids and FAs.
- And a spare charger or if the child is younger her (spare) cuddly toy.

This information is not a substitute for qualified medical information, as with any illness in FA, always consult your doctor if you have any concerns about your health.

Adapted from International Friedreich's Ataxia Parents group - 30th March 2020