

NIHR Clinical Research Facility

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Do's and don'ts for neuromuscular patients post AAV-gene therapy

- Avoid contact with people who have symptoms of respiratory infections (cold, cough, and flu-like symptoms, etc.) or gastrointestinal conditions (diarrhoea and vomiting).
- Should someone in the household be ill; keep the sick person in a separate room from your child, if possible.
- Wash hands often and thoroughly with soap and water. If soap and water are not available, use an alcohol-based hand rub.
- Continue to schedule routine care with your paediatrician, neurologist, and pulmonologist to closely monitor your child's health and keep them informed of your child's active participation in a gene clinical therapy trial.
- If you are concerned that your child may have respiratory complications (weak cough, difficulty breathing, bluish discoloration), please seek emergency care.
- If your child has been prescribed steroids, ensure you have enough steroids at home until your next research appointment
- Discuss vaccinations with your study team before going ahead with them
- Discuss with the study team attending school/ nursery in the period immediately before, and after dosing

Emergency contact is to ring CRF in hours 8-6 Monday to Friday (except bank holiday) out of these hours call hospital switchboard 02074059200 and ask to speak to the neurology doctor on call.**