

# Precautions for SCID patients or severe T cell deficiency patients – Information for Parents

## 1 BACKGROUND

Children with SCID are extremely susceptible to potentially life threatening opportunistic infections.

- Children/infants with SCID must be nursed in isolation at all times when in hospital - (cubical doors to remain closed)
- Children must not wait in open areas e.g. X-ray, A&E if admitted to hospital
- All Staff must pay strict attention to hand washing and wear plastic aprons.
- Visitors must be kept to a minimum
- All staff and visitors should be free of infection (e.g. Colds, Flu, cold sores)
- **IMMUNISATIONS MUST NOT BE GIVEN**
- Once your child is home your local hospital or Community nurse must be notified immediately if your child comes into any contact with chicken pox, shingles, measles etc.

## 2 PRECAUTIONS TO TAKE ONCE DISCHARGED HOME:

### 2.1 Household cleaning and laundry:

- Normal weekly household cleaning using antibacterial agent on all the kitchen surfaces.
- Normal household dust is not harmful and weekly dusting is recommended. Building dust can contain a harmful fungus called Aspergillus, so no building work should take place in the home.
- Laundry should be dried thoroughly, ideally indoors in a room that is well ventilated, this will prevent damp and reduce the risk of fungus developing.
- Laundry can be dried outside but not whilst your child is undergoing Bone Marrow Transplantation or when neutropenic.

### 2.2 Feeding and equipment:

- All feeding equipment should be cleaned in hot soapy water and then steam sterilised. Milton Tanks **must not** be used due to the risk of growing pseudomonas.
- All water needs to be boiled and allowed to cool before adding to feeds, flushing NG tubes or giving to your child to drink. Bottle mineral water is **not** allowed. Water can be boiled and kept for 24 hours as long as the container being used to store the water has a lid. This can either be stored in the refrigerator or at room temperature.
- NG tubes and milk sets are to be single use only for your child.

### 2.3 Isolation precautions at home:

- Keep the number of visitors at one time to a minimum
- Restrict contact of school age children that come to the home to reduce the risk of chicken pox or measles contact. If your child has had contact with chicken pox or measles, you need to inform one of the Clinical nurse specialists **immediately** 0207 405 9200 Ext 5024/8834 or immunology medical team on cisco phone 6313 and we will advise if treatment or prophylaxis is required.
- Adhere to strict hand washing with an antibacterial soap at home including all visitors.
- All visitors should be infection free or should not visit if they do not feel well. This includes coughs, colds, cold sores, any diarrhoea or vomiting illness. If anyone has had vomiting illness or diarrhoea, they should have no contact for 48 hours.

- **DO NOT** travel on public transport
- Avoid crowded and busy areas such as shopping centres; if you need to go to the local shops you can put the rain cover as protection over the pram/pushchair. Avoid peak and busy times.
- Your child can go to parks and open spaces WHEN LESS CROWDED

### 3 MONITORING REQUIRED ONCE DISCHARGED HOME – THIS WILL BE ARRANGED BEFORE DISCHARGE:

#### 3.1 Weekly routine monitoring:

- FBC with manual differentiation
- U+Es, LFTs
- Virology PCRs for EBV/ADENO/CMV DNA by PCR

#### 3.2 If your child becomes unwell at home the following investigations should be performed promptly:

- Full septic screen, FBC, U&Es, LFTs, CRP, Urine for MC+S, Stools for virology & Microbiology, Blood cultures, Virology PCRs EBV/ADENO/CMV DNA by PCR. If symptomatic of a respiratory infections, NPA and chest X-ray.

#### 3.3 If your child has a central line we will:

- Commence broad spectrum antibiotics as per our neutropenic protocol irrespective of neutrophil count.
- Daily blood cultures need to be taken
- Continue IV antibiotics for 10 days from the 1<sup>st</sup> negative culture
- If the child is well, administration of IV antibiotics should be continued as an outpatient (either by CCN or on ward)

#### 3.4 Common reasons for admissions:

Please contact the Clinical nurse specialists immediately 0207 405 9200 Ext 5024 or immunology medical team on cisco phone 6313 for any of the following

- Pyrexia (fever) over 38°C for 4 hours,
- Temperature of 38.5°C on one occasion,
- Diarrhoea and vomiting,
- Respiratory infections,
- Rashes.

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