Guidance Sheet 10:

Parent Training





Parent Training

It is the responsibility of the site staff to train parents how to administer the spray, take swabs and transport them, use the WheezeScan and App.

Training is considered complete when site staff are confident that parents can undertake all of the BALLOON procedures without supervision.

Key points training should cover:

- Parents are aware how to administer the spray including timing (please refer to parent guidance sheet for more information).
- Parents are aware of how to store the spray and keep any empty sprays for their research nurse.
- Infants will be able to have all medicines and supplements they would normally have.
- The BALLOON app is downloaded (if being used) and that parents are aware of how to use it, or an alternative method of reporting agreed e.g. paper diary.
- Parents know how they will receive more sprays and how to get in touch if they have an issue or need replacement supplement.
- Parents know who to contact for queries relating to the trial, and who to contact for clinical queries.
- Parents know how and when to use the WheezeScan (please refer to parent guidance for more information).
- Parents know how and when to take swabs and how to send to them the labs (please refer to parent guidance for more information).

Parents should contact the recruiting site if they require further training or guidance and can also be signposted to the BALLOON website which includes a number of resources.

Documenting Parent Training

Sites should document that training has taken place in the infant's medical notes.

Support for families post-discharge

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At discharge, ensure parents are given the BALLOON Parent Discharge Pack containing:

- A supply of sprays (two).
- Wheeze Scan.
- A supply of 3 swabs, forms and padded addressed and stamped envelopes.
- Written support material (Parent Guidance Sheet) and resources (sites can also signpost to the BALLOON study website for online resources).
- Contact information for their local research nurse and PI (on the bottom of the Parent Guidance Sheet).
- The method, date and time of the next planned contact with the research nurse.
- A paper diary for recording (if using this as alterative to study app).
 - Emergency Card.

Parents should be signposted to online information on the BALLOON website.

Families will be supported throughout the trial by their local NHS clinical teams as per usual care. This may include the neonatal team, paediatricians, outreach nurses. The recruiting site are responsible for supporting an infant throughout the trial.

Parents should be provided with information on who to contact with trial-related queries; this should be either the local research nurses or the local post-discharge clinical team, depending on local set up.

Letters

An electronic version of the GP letter is provided to sites. Please update with the participant's details and send to the GP.

Study app

The BALLOON study app can be used by parents throughout the study period to:

- Report spray adherence (whether they have given spray);
- Record any respiratory or non-respiratory illnesses and/or symptoms;
- Report unplanned hospital admissions.

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The BALLOON study app is the preferred method for parents to record trial information where possible. If parents are not able to, or do not wish to use the study app, there are agreed alternative methods for reporting this information. Please ensure you notify the BALLOON Trial Manager (kotechasj@cardiff.ac.uk) if the parents are not going to be using the App.

The app is not used for re-ordering sprays.

Please add the parent's email address and the requested details to the Your Research Portal. Parents will then receive an email with guidance on how to download the App. Please ensure they have successfully downloaded and logged into the App. Parents can each use the app on separate handsets for the same infant.

Parents or site should report any problems or queries relating to the study app to the BALLOON study team.

Reporting lower respiratory tract infections (LRTI) and hospital admissions

Parents are asked to report any LRTI and hospital admissions for the period of spray usage (until 1 year corrected age).

Parents using the study app can report any LRTI for their infant through the app (sites and the BALLOON study team will receive a notification). Parents using paper diaries should report LRTI local clinical team.

Sites should verify the LRTI and ensure swabs are taken.