Typical Patient Journey for a Child with a Bilateral Cleft Lip and Palate (BCLP)

<table>
<thead>
<tr>
<th>Age</th>
<th>Ante-natal Diagnosis</th>
<th>Birth</th>
<th>0-2 months</th>
<th>3-4 Months</th>
<th>6-9 Months</th>
</tr>
</thead>
<tbody>
<tr>
<td>South Wales South West Managed Clinical Network</td>
<td>Referral to Cleft Team The Cleft Specialist Nurse will make contact within 24 hours of referral. Offer of 4D Scan</td>
<td>Maternity Unit Referral to Cleft Team on the day of birth Cleft Nurse visits baby within 24 hrs of referral to offer feeding help and information. Newborn Hearing Screening test at local hospital</td>
<td>New Baby Clinic Initial Assessment. Parents introduced to the Team which includes the Surgeon, Anaesthetist, Paediatrician, Psychologist and Cleft Nurses Referral to Genetics if indicated</td>
<td>Inpatient stay Surgery: Lip Repair Pre/Post op Photos Speech Therapy advice given</td>
<td>Inpatient stay Surgery: Palate Repair Speech Therapy advice given Hearing test at local hospital at approx 9 months</td>
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The Cleft Nurse in contact with the family as required and offers a 7 days per week service

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<tr>
<th>Age</th>
<th>5 years</th>
<th>3 years +</th>
<th>18 months - 5 years</th>
<th>9-24 Months</th>
<th>9-12 Months</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ante-natal Diagnosis</td>
<td>Cleft MDT Clinic Assessment and review by: Surgeon (+ photos taken) Audiologist (for hearing test) Speech Language Therapists (+ recordings) Orthodontist (+ models taken) Paediatric Dentist Psychologist</td>
<td>Hearing tests at 18 mths and 3 yrs at local hospital</td>
<td>Speech &amp; Language Therapy Assessment, reviews at 18mths, 3.4, and 5 years and therapy following surgery From 18 months: Some children will need speech therapy - this will be arranged locally</td>
<td>Babble Workshop at 9-12 months combined with advice given by the Dental Health Educators</td>
<td>12 months: Cleft Review Clinic Review of Surgery, Post op Lip Photos taken Appointment with Paediatric Dentist</td>
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At 3 yrs old: Appointment with Paediatric Dentist At 2 yrs old: Appointment with Paediatric Dentist and Psychologist

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<tr>
<th>Age</th>
<th>7 years</th>
<th>7-11 years</th>
<th>8 years</th>
<th>10 years</th>
</tr>
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<tr>
<td>Ante-natal Diagnosis</td>
<td>Cleft MDT Clinic Review by: Surgeon/Orthodontist (to discuss whether an alveolar bone graft is needed to repair the gap in the bone) X-rays Paediatric Dentist Psychologist</td>
<td>7-10 years Orthodontics Preparation for alveolar bone grafting if needed 8 years old: Appointment with Paediatric Dentist</td>
<td>8-11 years Inpatient Stay (if required) Surgery: Alveolar Bone Graft to repair gap in bone of upper jaw Outpatient 6 month follow-up of surgery with x-ray on Cleft MDT clinic</td>
<td>Cleft MDT Clinic Assessment and review by: Surgeon (+ photos taken) Audiologist (for hearing test) Speech Therapists (+ recordings) Orthodontist (+ models taken) Paediatric Dentist Psychologist</td>
</tr>
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</table>
It is very important to recognise that every child is an individual and will follow their own unique journey. This is a guide, and all dates are approximate.

At any stage, please feel free to ask the Cleft Team “where have we got to?” or “what happens next?”.

Cleft MDT Clinic
Assessment and review by:
- Surgeon (+ photos taken)
- Audiologist (for hearing test)
- Speech & Language Therapists (+ recordings)
- Orthodontist (+ models taken)
- Psychologist
- Restorative Dentist if needed

Cleft MDT Clinic
Assessment and review by:
- Surgeon (+ photos taken)
- Audiologist (for hearing test)
- Speech & Language Therapists (+ recordings)
- Orthodontist (+ models taken)
- Psychologist
- Offer of Genetic Referral

Joint Appointment at 12 yrs with
- Paediatric Dentist
- Orthodontist

Orthodontics
Treatment appointments as required.

Additional Notes

About Inpatient stays: All inpatient stays will normally be in Morriston Hospital. You can expect to see the surgeon before and after the operation. The speech and language therapist and specialist nurse will visit you on the ward as well.

MDT = Multi-Disciplinary Team
SLT = Speech and Language Therapy

Alveolus / Alveolar = the bone around the teeth

Other Surgery: Some children may require other operations during their patient journey. These might include an operation to improve speech, to improve the appearance of the lip or nose. These options will be discussed with you should the need arise.

About Bone Grafts and Osteotomies: Most children with BCLP are recommended to have an alveolar bone graft. A smaller number are recommended later to have an Osteotomy to correct the position of the jaw or jaws. This is called Orthognathic Surgery

Hearing Assessments: In addition to the hearing assessments indicated above, further assessments will be carried out at intervals as appropriate throughout childhood.

Speech and Language Therapy: In addition to the speech assessments indicated above, further assessments may be carried out and/or your child may be referred to Speech Therapy at any time. Occasionally treatment is carried out jointly with the Restorative Dentist (for example, when a Speech Bulb is required)

Psychology: The Cleft Team Psychologist can be contacted at any other time during the patient journey to discuss any worries or concerns

Cleft Coordinator: Can be contacted on 01792 703810 (answering machine for outside normal working hours)

South Wales Cleft Team Web Site: http://www.wales.nhs.uk/cleft-team