

# HA Convention 2016

## QEH experience in universal neonatal screening for IEM



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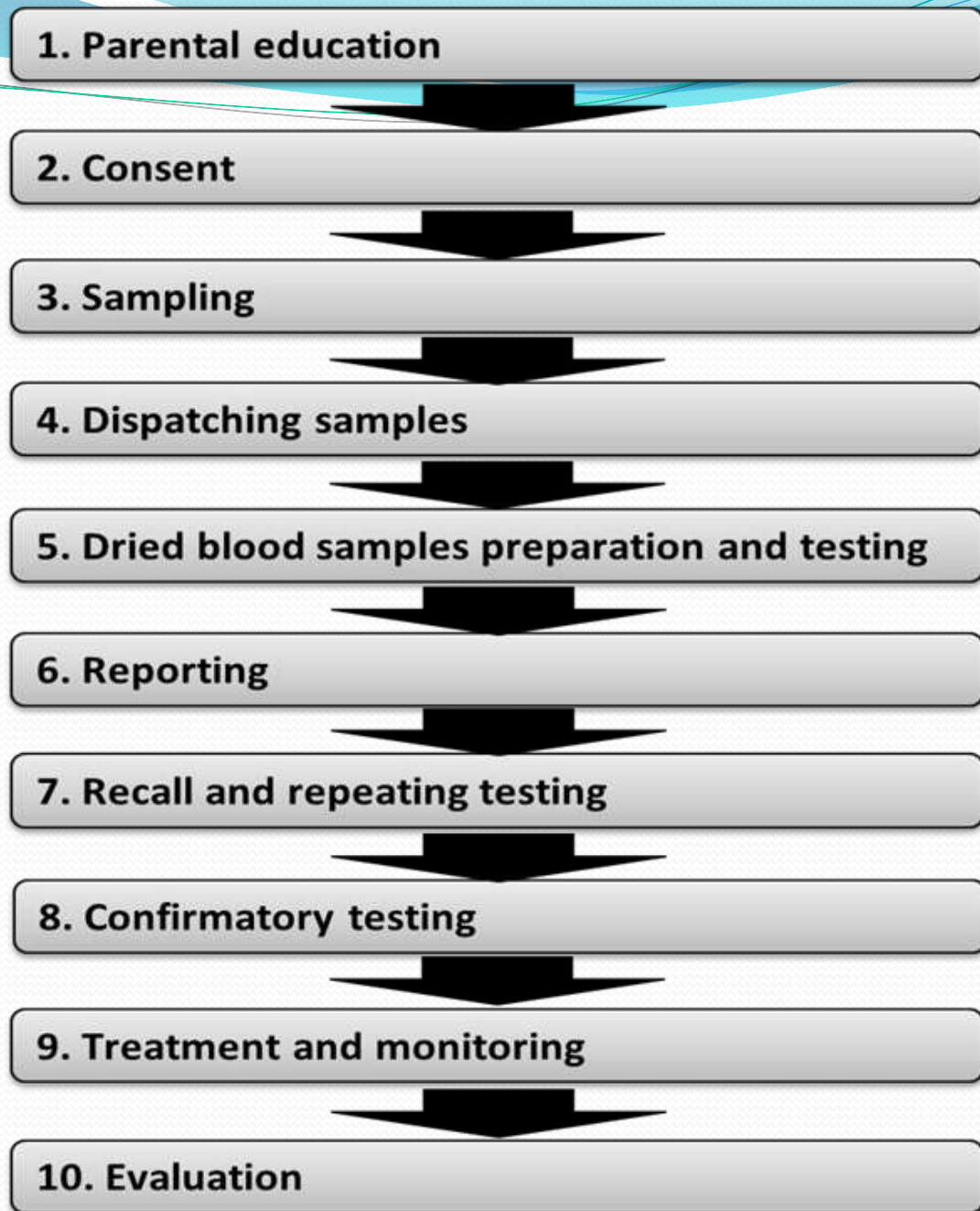
# Background

- Severe
- ~1:2,500 births
- HK lags way behind many places
- PWH is running a self-paid service

# Pilot in QEH

- 4Q 2015
- 6,000 deliveries per year
- IEM clinic (paed)
- IEM program to future New Children Hospital

# Workflow



Step	Main task(s)	Issue(s)
1. Parental education	<ul style="list-style-type: none"> <li>Information delivery and education about the NBS</li> </ul>	<ul style="list-style-type: none"> <li>Preparation of the education materials and programme</li> <li>Timing (AN/PN)</li> <li>Involved parties (<b>Obstetrics</b>)</li> </ul>
2. Consent	<ul style="list-style-type: none"> <li>Obtain consent</li> </ul>	<ul style="list-style-type: none"> <li>Tailor-made consent for expanded NBS</li> <li>Content (type of diseases screened, ownership of residual blood spots, storage of residual blood spots, duration of shortage and future use of stored samples)</li> <li>Timing (AN/PN/just before blood sampling)</li> <li>Group vs individual face-to-face</li> <li>Involved parties (<b>obstetrics &amp; Paediatrics</b>)</li> <li>Staffing</li> <li>Training to staff of involved parties</li> </ul>
3. Sampling	<ul style="list-style-type: none"> <li>Blood spot sampling</li> </ul>	<ul style="list-style-type: none"> <li>Timing of blood taking (<b>48 hours after birth, took milk</b>)</li> <li>Method</li> <li>Involved parties (<b>Obs &amp; Paed</b>)</li> <li>Staffing (<b>phlebotomist</b>)</li> <li>Training to staff of involved parties</li> </ul>
4. Dispatching samples	<ul style="list-style-type: none"> <li>Transportation of blood samples to laboratory</li> </ul>	<ul style="list-style-type: none"> <li>Any special arrangement (<b>Obs</b>)</li> </ul>
5. Dried blood samples preparation and testing	<ul style="list-style-type: none"> <li>Samples preparation and testing in expanded NBS laboratory</li> </ul>	<ul style="list-style-type: none"> <li>Availability of accredited and capable laboratory</li> <li>Equipment and resources</li> <li>Staffing (<b>chemical pathologist</b>)</li> <li>Involved parties</li> <li>Training to staff of involved parties</li> </ul>

Step	Main task(s)	Issue(s)
6. Reporting	<ul style="list-style-type: none"> <li>Results are interpreted and reported by <b>Chemical pathologists</b></li> </ul>	<ul style="list-style-type: none"> <li>Turn-around time</li> <li>Involved parties</li> <li>Communication among involved parties</li> </ul>
7. Recall and repeat testing	<ul style="list-style-type: none"> <li>Recalling screening positive cases and taking blood for repeat testing</li> </ul>	<ul style="list-style-type: none"> <li>Urgency of recall</li> <li>Urgency of repeat blood taking</li> <li>Urgency of laboratory testing</li> <li>Contingency management of suspected baby</li> <li>Staffing</li> <li>Involved parties (e.g. <b>Paediatricians</b>)</li> <li>Training to staff of involved parties</li> </ul>
8. Confirmatory testing	<ul style="list-style-type: none"> <li>Diagnostic</li> </ul>	<ul style="list-style-type: none"> <li>Method</li> <li>Staffing</li> <li>Involved parties (<b>Patho</b>)</li> <li>Training to staff of involved parties</li> </ul>
9. Treatment and monitoring	<ul style="list-style-type: none"> <li>Continuous management and monitoring</li> </ul>	<ul style="list-style-type: none"> <li>Availability of treatment protocols</li> <li>Staffing</li> <li>Involved parties (<b>Paed</b>)</li> <li>Training to staff of involved parties</li> </ul>
10. Evaluation	<ul style="list-style-type: none"> <li>Assessing the outcomes and result of the programme</li> </ul>	<ul style="list-style-type: none"> <li>Aims of evaluation</li> <li>Scope of evaluation</li> <li>Staffing</li> <li>Involved parties</li> </ul>

# Issues

- Workflow: parental education, consent, sampling
- Mechanism to screen all eligible: check list
- Transportation
- Resources
- Education: lectures, visit

# Call back if abnormal result

- Panic
- Wrong or answered telephone number
- Which telephone number- registered in HA?  
Additional? Self input?



# Involvement of doctors

- More patients? Quota
- Questions in antenatal: available? Arrangement?
- Family history: PDC?
- Early discharge
- Results of IEM screening in postnatal
- Education
- Staff engagement

Thank you