This form is used in the child death review process to gather detailed information about children who die as the result of a chromosomal, genetic or congenital anomaly, excluding cardiac conditions. For children with a cardiac condition who have died please use the Cardiac: Congenital or Acquired Supplementary Reporting Form.

The primary purpose of this form is to enable CDOP to review all children's deaths in this category in their area in order to understand patterns and factors contributing to children's deaths. Please complete those questions on which you hold information. If you do not have information for a particular item, please tick “Not known”.

Information on this form will be shared with other professionals for the purposes of the child death review process. All professionals are entitled to share this information without contravening laws on data protection. All information gathered will be stored securely and statutory safeguards (s251) are in place to allow the legal transfer, storage, analysis of identifiable data.

**Identifying details** **- to be removed for the purposes of anonymisation prior to discussion at the CDOP:**

|  |  |  |  |
| --- | --- | --- | --- |
| Name |  | Date of birth(dd/mm/yyyy) |  / /  |
| NHS No. |  | Date and time of death | Date: / / Time: **:** (24hr) |
| Postcode |  |

|  |  |
| --- | --- |
| Which primary diagnosis sub-category did this child fall into? *(Please choose* ***ONE*** *option)* | ☐ Chromosomal abnormality *(please specify)*☐ Single gene defect (including mitochondrial)  *(please specify)*☐ Other known genetic condition *(please specify)*☐ Other named syndromes or disease *(please*  *specify)*☐ Other, e.g. Presumed Syndrome Without a Name  (SWAN) *(please specify)* |
| Was this condition diagnosed antenatally? | ☐ Yes☐ No☐ Not known |
| If **yes**, what was the mode of diagnosis? | ☐ Ultrasound scan☐ Chorionic villus sampling[ ]  Trisomy Screening[ ]  Free Fetal DNA Trisomy Test☐ Other *(please specify)*☐ Not known |
| If **no**, please specify when first diagnosed: | ☐ Birth to 12 months☐ 1 – 4 years ☐ 5 – 9 years☐ 10 – 14 years ☐ 15 – 17 years  |
| Following the diagnosis, were the parents offered the opportunity to discuss the diagnosis? | ☐ Offered and accepted☐ Offered and declined☐ Not offered☐ Not known |
| Was folic acid taken peri-conceptually by the child's mother? | ☐ Yes☐ No☐ Not known |
| If the mother was on any medication during pregnancy, please give details. |  |
| Was there history of this condition in the family?  | ☐ Yes, first degree family member (i.e. parents, siblings)☐ Yes, second degree or further family member (i.e.  maternal / paternal grandparent, uncle, aunt)☐ No☐ Not known |
| Was there a history of any other chromosomal, genetic or congenital anomalies in the family? | ☐ Yes, first degree family member (i.e. parents,  siblings)☐ Yes, second degree or further family member (i.e.  maternal / paternal grandparent, uncle, aunt)☐ No☐ Not known |
| Was this child affected by a probable or definite autosomal recessive condition? | ☐ Yes *(go to next question)*☐ No *(go to question: Have the family been offered the* *opportunity to discuss a plan for future pregnancies?)*☐ Not known *(go to question: Have the family been offered* *the opportunity to discuss a plan for future pregnancies?)* |
| Was an urgent genetics referral offered? | ☐ Previously referred so a new referral was not necessary *(go to next question)*☐ Referral not necessary given nature of condition *(go to question: Have the family been offered the opportunity* *to discuss a plan for future pregnancies?)*☐ Yes: referred *(go to next question)*☐ Yes: referral offered but declined *(go to question: Is* *there evidence that the parents had all the information* *necessary to make this decision and that it was presented in a* *culturally competent, sensitive and understandable way?)*☐ No: referral not offered (please give details): *(go to question: Have the family been offered the opportunity* *to discuss a plan for future pregnancies?)* ☐ Referral was offered but delayed due to COVID-19 arrangements (please give details): *(go to question: Have the family been offered the opportunity* *to discuss a plan for future pregnancies?)* ☐ Not known *(go to question: Have the family been offered* *the opportunity to discuss a plan for future pregnancies?)* |
| Have the family been seen by the genetics service? | ☐ Yes, they were referred and seen *(go to question:* *Have the family been offered the opportunity to discuss a plan* *for future pregnancies?)*☐ Yes, they were referred but were not seen prior to the child’s death (e.g. awaiting assessment) *(go to* *question: Have the family been offered the opportunity to* *discuss a plan for future pregnancies?)*☐ Other (please give details): *(go to question: Have the family been offered the opportunity* *to discuss a plan for future pregnancies?)*  |
| Is there evidence that the parents had all the information necessary to make this decision and that it was presented in a culturally competent, sensitive and understandable way? e.g. use of interpreter as required, use of written materials, decision-making aids | ☐ Yes☐ No (please give details):☐ Not known |
| Have the family been offered the opportunity to discuss a plan for future pregnancies?  | ☐ Yes, accepted☐ Yes, declined *(please specify if reason given)*☐ No *(please specify if reason given)*☐ Not yet, but intended☐ Not known |
| Have the family been offered genetic counselling following the death?  | ☐ Previously referred so a new referral was not necessary☐ Referral not necessary given nature of condition☐ Yes: referred☐ Yes: referral offered but declined☐ No: referral not offered ☐ Referral was offered but delayed due to COVID-19 arrangements☐ Not known |