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Lampiran 1. Kuesioner Data Dasar dan Pemantauan Penelitian

Identitas Pasien Tanggal Pengambilan data :(RM :.....)

1. Nama : Jenis Kelamin : (L / P) Usia ibu hamil.....
2. Berat badan lahir : < 1500 gr... 1500-2500 gr.... > 2500 gr.....
3. Sesuai masa kehamilan Kecil Masa Kehamilan
4. Tempat Tanggal Lahir :
5. BB : PB/TB :
(BB/U PB/U BB/PB → usia 0-3 tahun)
(BB/U PB/U BMI/U.... → usia 3-18 tahun)
6. Status Gizi :< P5 : Gizi Buruk, P5-25 : Gizi Kurang
P25-50 : Baik P 50-95 : Overweight > P95 : Obesitas
7. Gambaran klinis *Down Syndrome*
 - 1) Kulit leher berlebih (*short neck*) : ada / tidak ada/ tidak ada data
 - 2) Sudut mulut menghadap ke bawah : ada / tidak ada/ tidak ada data
 - 3) Hipotonia : ada / tidak ada/ tidak ada data
 - 4) Wajah datar (*flat face*) : ada / tidak ada/ tidak ada data
 - 5) Telinga displastik (*displastic ear*) : ada / tidak ada/ tidak ada data
 - 6) Lipatan epicanthus mata (*epicanthic fold*) : ada / tidak ada/ tidak ada data
 - 7) Gap antara jari kaki pertama dan ke dua (*sandal gap*) ada / tidak ada/ tidak ada data
 - 8) Lidah protursi (*protruding tongue*) : ada / tidak ada/ tidak ada data

SKOR (Jumlah ada Gambaran Klinis 1-8) :

Kesimpulan

- 0-2 : SD dieksklusi, tidak perlu investigasi lebih lanjut ☐
- 3-5 : Dicurigai Sindrom Down, analisis kromosom segera ☐
dibutuhkan untuk menegakkan/mengeksklusi diagnosis
- 6-8 : Klinis terbukti Sindrom Down. orang tua diberitahu ☐

- 9) *Simian Line* : ada / tidak ada/ tidak ada data
- 10) *Low set ear* : ada / tidak ada/ tidak ada data
- 11) *Umbilical Hernia* : ada / tidak ada/ tidak ada data

8. Pemeriksaan Genetik : Ya / Tidak , Hasil :

- 1) *Trisomi 21* murni ☐
- 2) *Mozaic* Sindrom Down ☐
- 3) Translokasi ☐
- 4) Lain-lain ☐

9. Faktor Yang mempengaruhi Kematian

- a. Usia saat meninggal :Tgl Masuk RS : Tgl. Keluar RS...
- b. Usia saat keluar rumah sakit (hidup) :Tgl Keluar RS :
- c. Jenis Kelamin : Laki-laki / Perempuan
- d. Gizi Buruk ($P < 5$) : Ya / Tidak
- e. Pneumonia : Ya / Tidak, Kultur :
Antibiotik :
- f. Penyakit Jantung Bawaan
Ekokardiografi : Ya / Tidak
Diagnosa (sesuai Ekokardiografi) :
AVSD : ... ASD : ... VSD : ... PDA : ... TOF :
PH : Atresia Pulmonal : ... Stenosis Pulmonal : Lain:
- g. Sepsis : Ya / Tidak
Kultur :
Antibiotik :
- h. Syok Septik :

10. Diagnosis Lengkap :
.....
.....

11. Kondisi saat ini : Mati / Hidup

12. Jika Mati Sebab Kematian :
Lama Rawat :
Lama Kematian (dari awal faktor risiko muncul) :

13. Bangsal Perawatan : PICU : Ya / Tidak