

Dear CHSD Data Managers,

The Core Group and surgeon leadership discussed the duplicate fields on the data collection form v3.41 and determined a process for documentation.

- For the Chromosomal Abnormalities of Trisomy 13, 18, and 21, please document them in the **Chromosomal Abnormalities section** of the Data Collection Form (yellow highlighted fields in screen shot below). Please do not document these chromosomal abnormalities using the Trisomy 13, 18, and 21 fields in the Syndromes section (blue highlighted, crossed out fields in screen shot below). However, the syndromes that correlate with each of these 3 chromosomal anomalies **should** be entered in the Syndromes section of the collection form {Patau syndrome (Trisomy 13), Edwards syndrome (Trisomy 18), and Down syndrome (Trisomy 21)}
- The following fields were erroneously added to the data collection form and should not be used. These fields will be removed at the next upgrade.
 - Familial atrial septal defects
 - Familial non-syndromic CHD
 - Non-syndromic CHD
 - Sporadic and familial CHD
 - Syndromic CHD
- A definition for the field 'Familial CHD' is being developed by the surgeon leadership and will be published soon.

CHROMOSOMAL ABNORMALITIES	
Chromosomal Abnormality: <i>(select all that apply)</i> ChromAb (570)	
<input type="checkbox"/>	No chromosomal or genetic abnormality identified
<input type="checkbox"/>	Known Mosaicism
<input type="checkbox"/>	11p15.5
<input type="checkbox"/>	1p36 del
<input type="checkbox"/>	11q
<input type="checkbox"/>	1q21.1 del
<input type="checkbox"/>	12p1.21
<input type="checkbox"/>	1q21.1 dup
<input type="checkbox"/>	12p12.1
<input type="checkbox"/>	1q42.1
<input type="checkbox"/>	12q24
<input type="checkbox"/>	2p21
<input type="checkbox"/>	15q11.2 del
<input type="checkbox"/>	3p22
<input type="checkbox"/>	15q21.1
<input type="checkbox"/>	3q dup
<input type="checkbox"/>	16p11.2 del
<input type="checkbox"/>	4p16
<input type="checkbox"/>	17p11.2 del
<input type="checkbox"/>	4q del
<input type="checkbox"/>	17q21.31 del
<input type="checkbox"/>	5p15.2 del
<input type="checkbox"/>	20p12
<input type="checkbox"/>	5p15.33 del
<input type="checkbox"/>	22q11 deletion
<input type="checkbox"/>	6p12
<input type="checkbox"/>	22q11.2 dup
<input type="checkbox"/>	7q11
<input type="checkbox"/>	45X0
<input type="checkbox"/>	7q11.23 del
<input type="checkbox"/>	47,XXY
<input type="checkbox"/>	7q11.23 dup
<input type="checkbox"/>	Monosomy X
<input type="checkbox"/>	7q32
<input type="checkbox"/>	Trisomy 08
<input type="checkbox"/>	7q34
<input type="checkbox"/>	Trisomy 09
<input type="checkbox"/>	8p23.1 del
<input checked="" type="checkbox"/>	Trisomy 13
<input type="checkbox"/>	8p23.1 dup
<input checked="" type="checkbox"/>	Trisomy 18
<input type="checkbox"/>	8q12
<input checked="" type="checkbox"/>	Trisomy 21
<input type="checkbox"/>	9q34.3 del
<input type="checkbox"/>	Other chromosomal or genetic abnormality

SYNDROMES	
Syndromes: (select all that apply) Syndrome (610)	
<input type="checkbox"/> Down syndrome (Trisomy 21)	<input type="checkbox"/> Duane Radial Ray (Okhiro) syndrome
<input type="checkbox"/> Duchenne Muscular Dystrophy	<input type="checkbox"/> Edwards syndrome (Trisomy 18)
<input type="checkbox"/> Ehlers-Danlos Syndrome	<input type="checkbox"/> Ellis-van Creveld syndrome
<input checked="" type="checkbox"/> Familial atrial septal defects	<input checked="" type="checkbox"/> Familial CHD
<input checked="" type="checkbox"/> Familial non-syndromic CHD	<input type="checkbox"/> Fetal alcohol syndrome (FAS)
<input type="checkbox"/> Fetal drug exposure	<input type="checkbox"/> Fetal rubella syndrome (Congenital rubella syndrome)
<input type="checkbox"/> Non-syndromic CHD	<input type="checkbox"/> Noonan syndrome
<input type="checkbox"/> Oculofaciocardiodental	<input type="checkbox"/> Oral-facial-digital syndromes (types I-XVI and unclassified)
<input type="checkbox"/> Trisomy 13	<input checked="" type="checkbox"/> Trisomy 18
<input checked="" type="checkbox"/> Trisomy 21	<input type="checkbox"/> Turner syndrome (45XO)
<input type="checkbox"/> VACTERL syndrome (VACTER/MATER/MATER)	<input type="checkbox"/> VACTERL-H syndrome (MATER association with)

Regarding the new procedures (listed below) added to v3.41 which do not have STAT scores; the surgeon leadership is determining a process for documenting these procedures. We will notify everyone on the process as soon as it is determined via email, in the Database News newsletter and on our website in the What's New section. Please stay tuned.

1. Coarctation repair, Descending aorta anastomosed to Ascending aorta (3460)
2. Coarctation repair, Extra-anatomic Bypass graft (3470)
3. DORV - AVC (AVSD) repair (3450)
4. DORV repair, No Ventriculotomy (3410)
5. DORV repair, RV-PA conduit (3440)
6. DORV repair, Ventriculotomy, Nontransannular patch (3420)
7. DORV repair, Ventriculotomy, Transannular patch (3430)
8. Double root translocation (3400)
9. Extended Ventricular Septoplasty (modified Konno, VSD creation and patch enlargement of LVOT, sparing aortic valve) for tunnel type sub aortic stenosis (3380)
10. LV Endocardial Fibroelastosis resection (3390)
11. PA, reconstruction (plasty), Branch, Peripheral (at or beyond the first lobar branch) (0550 Wording was changed from v3.3)
12. PA, reconstruction (plasty), Branch, Peripheral (at or beyond the first lobar branch, beyond the first segmental branch) (3360)
13. PA, reconstruction (plasty), Branch, Peripheral (at or beyond the first lobar branch, proximal to first segmental branch) (3370)
14. RV Rehabilitation, Endocardial Resection (3370)
15. TOF repair, Ventriculotomy, Transannular patch, plus native valve reconstruction (3330)
16. TOF repair, Ventriculotomy, Transannular patch, with monocusp or other surgically fashioned RVOT valve (3340)