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| **Number** | **Age at Last Visit** | **Race/**  **Ethnicity** | **Sex** | **CHD Diagnosis** | **Age of Initial Genetics Evaluation** | **Seen by geneticist** | **Seen by GC** | **NDD** | **Extra-cardiac anomalies** | **Karyotype** | **SNP Microarray** | **Gene Panel** | **Exome Sequencing** | **Follow up** |
| 1 | 10 years, 0months | Non-Hispanic white | Male | Tricuspid stenosis | 1 year old | Yes | Yes | fine motor delay, mild gross motor delay | Tracheoesophageal fistula, posterior left 6th/7th rib fusion, low set and posteriorly rotated ears, Anisocoria ?VACTERL | No | Yes (2012) | No | No | Seen one time |
| 2 | 10 Years,10 months | Non-Hispanic white | Female | Hypoplastic right ventricle, large VSD | 22 months | Yes | Yes | Speech delay and ADHD | Ureterocele that was incised and anorectal fistula (s/p PSARP, Levitt, 69/20/10) and left upper pole nephroureterectomy in 01/2013 and has been discharged from urology care | No | Yes (2010) | *ZIC3* and *SALL1* sequencing (2012) | No | None |
| 3 | 10Years, 11 months | African American/Black | Male | HLHS | 2 years old | Yes | Yes | GDD and learning difficulties. IQ 80 | ADHD, adjustment disorder; seizures secondary ischemic event | No | No- F.D. | No | No | None |
| 4 | 10 years, 4 months | Non-Hispanic white | Male | DORV, Unbalanced atrioventricular canal | 4 days old | Yes | Yes | Y- fine motor and gross motor delay | Heterotaxy with asplenia, malrotation. bronchoscopy and ciliary biopsy (nasal brush biopsy) which showed cilia with normal ultrastructure, and anticipated finding given the specific mutation. | No | Yes (2011) -14.0 Mb region of homozygosity of 7p21.1p15.1 | Heterotaxy panel (2011)  4 genes  *DNAH11* gene sequencing (2011): homozygous c. 4348C>T p.Arg1450Stop- Primary ciliary dyskinesia | No | Seen multiple times |
| 5 | 10 years, 4 months | Non-Hispanic white | Female | Tricuspid atresia | 2 months | Yes | Yes | GDD | Dysmorphic, Tracheobronchomalacia, developmental delay, hypotonia, and scoliosis, intermittent esotropia, hyperopia, and astigmatism. G-tube fed due to poor growth, lung collapse as a newborn | Yes (2011) | Yes (2010) | *ZIC3* sequencing (2011) | No | Seen one time |
| 6 | 10 years, 4 months | Non-Hispanic white | Female | Unbalanced atrioventricular canal | 3 days old | Yes | Yes | Learning difficulty, ADHD, ODD | Left grade 2 VUR | No | Yes (2011) | No | No | Seen one time |
| 7 | 10 years, 5 months | Non-Hispanic white | Female | Pulmonary atresia with intact ventricular septum | 2 days old | Yes | Yes | Gross motor delay | None | No | Yes (2010) | No | No | Seen one time |
| 8 | 10 years, 6 months | Non-Hispanic white | Male | Ebstein anomaly | None | No | No | GDD, ADHD, IQ of 53 | Sensoneural hearing loss | No | Yes (2011)- 22q11.2 duplication | No | No | None |
| 9 | 10 years, 9 months | Non-Hispanic white | Female | Unbalanced AV Canal | None | No | No | Learning difficulty, ADHD, IQ 81 | Heterotaxy | No | No | No | No | None |
| 10 | 10 years, 9 months | Non-Hispanic white | Male | HLHS | None | No | No | No | Short stature, low weight; protein losing enteropathy | No | No | No | No | None |
| 11 | 11 years, 0 months | Non-Hispanic white | Male | single ventricle with unbalance AV canal | 3 days old | Yes | Yes | GDD | Heterotaxy syndrome with asplenia and situs inversus totalis, GDD, sleep disturbance,hypotonia, feeding and growth concerns with swallowing difficulties | No | Yes (2010) | Yes (2010)- Heterotaxy panel  4 genes | No | Seen one time |
| 12 | 11 years, 11 months | Non-Hispanic white | Male | Tricuspid Atresia | 2 years old | Yes | Yes | GDD, ADHD and Anxiety. Learning concerns, IQ was 87 | Café au lait macules and axillary freckling, VCUR, (no signs of heterotaxy besides TGA) | No | Yes (2012) | Heterotaxy panel  (2012)  4 genes  *NF1* and *SPRED1* (2018) | No | Seen multiple times |
| 13 | 11 years, 3 months | Non-Hispanic white | Male | HLHS | 23 months | Yes | Yes | GDD; | Persistent fetal pads on the majority of his digits and toes, with otherwise no findings, encephalopathy | Yes (2010) | Yes (2010)- 273 kb on chromosome 4q28.3 deletion. Mother also has it but asymptomatic | No | No | None |
| 14 | 11 years, 5 months | Hispanic | Female | Unbalanced AV Canal with a severely hypoplastic left ventricle | None | No | No | Yes | Heterotaxy, spleen visible, scimitar syndrome including hypoplastic right lung, | No | No | No | No | None |
| 15 | 11 years, 9 months | Non-Hispanic white | Female | Ebstein anomaly | None | No | No | Fine motor delay, speech delay, learning difficulty, ADHD. IQ of 82 | No | No | No | No | No | None |
| 16 | 11 years, 9 months | Non-Hispanic white | Male | HLHS | None | No | No | No | Short stature and low weight, ADHD | No | No | No | No | None |
| 17 | 12 years, 0 months | Non-Hispanic white | Male | HLHS | 4 years old | Yes | Y | Fine motor and gross motor delay; IQ of 97 | History of IVH with VP shunt, communicating hydrocephalus, short stature | Yes (2009) | Yes (2013) | No | No | None |
| 18 | 12 years, 0 months | Non-Hispanic white | Female | Unbalanced atrioventricular canal | Neonate | Ys | Yes | Has IEP | Inferior iris and inferior retinal colobomas, brain MRI normal - diagnosed with CHARGE | Unknown | Unknown | Unknown | Unknown | None |
| 19 | 6 years, 10 months | Non-Hispanic white | Male | Double inlet left ventricle | Never seen | No | No | No | Small left kidney (but within realm of normal) and hemoglobin D- Los Angeles trait | No | No | No | No | None |
| 20 | 7 years, 10 months | Non-Hispanic white | Female | DORV | 4 days old | Yes | Yes | GDD | Dextrocardia hypotonia, OSA | No | Yes (2013) | Heterotaxy panel (2013)  4 genes | No | None |
| 21 | 7years, 5 months | Non-Hispanic white | Female | HLHS | 3 days old | No | Yes | No- IQ 103 | Mullerian anomaly of uterus - renal US 2014 "Incidental note made of two uterine horns extending down to the level of the cervix. This could represent a bicornuate bicollis uterus or perhaps uterus didelphys | No | Yes (2013) | No | No | None |
| 22 | 7years, 5 months | Non-Hispanic white | Male | Pulmonary atresia | Never seen | No | No | No | Acute liver failure with gallbladder concerns | No | No | N | No | None |
| 23 | 7 years, 7 months | Non-Hispanic white | Male | Other underlying cardiac dx | 8 days old | Yes | Yes | GDD and ADHD | Dysmorphic, immune deficiency requiring weekly IgG, OSA, hypotonia | Yes (2014) | Yes (2013) - 597 kb interstitial deletion of 16p11.2 | No | No | Seen one time |
| 24 | 7 years, 9 months | Non-Hispanic white | Male | HLHS | Never seen | No | No | DD and ADHD; IQ 89 | Feeding difficulties | No | No | No | No | None |
| 25 | 7 years, 9 months | Black | Male | Pulmonary Atresia, Tricuspid Atresia | 2 days old | Yes | Yes | GDD and autism | Myopia | No | Yes (2013) | No | No | None |
| 26 | 8 years, 1 months | Non-Hispanic white | Male | DORV | 5 days old | Y | Yes | ADHD combined type, gross motor and fine motor delay, articulation concerns | No | No | Yes (2013) | No | No | None |
| 27 | 8 years, 1 months | Non-Hispanic white | Female | HLHS | 2 years old | Yes | Yes | GDD | Factor 7 deficiency, platelet dysfunction | No | Yes (2016) | *F7* gene sequencing (2017):  Heterozygous for c.325-324ins10 | No | None |
| 28 | 8 years 2 months | Non-Hispanic white | Female | HLHS | 1 month | No | Yes | Gross motor delay, speech articulation concerns | Hypotonia | No | Yes (2013) | No | No | None |
| 29 | 8 years, 2 months | Non-Hispanic white | Male | HLHS | 2 day old | No | Yes | Gross motor delay | None | No | Yes (2013) | No | No | None |
| 30 | 8 years, 3 months | Non-Hispanic white | Female | DORV | 6 day old | Yes | Yes | GDD, anxiety, ADHD, IQ 89 | Heterotaxy- dextrocardia with asplenia , | Yes (2012) | Yes (2012) | Yes (2012)- Heterotaxy- VUS in *CFC1* (c.433G>A)  Reanalyzed variant- benign | No | None- family did not want to be seen |
| 31 | 8 years, 3 months | Non-Hispanic white | Male | Tricuspid Atresia | 2 days old | No | Yes | Yes GDD, ADHD, learning problems, speech sound disorder | Failure to Thrive needing g-tube | No | No- F.D. | No | No | None |
| 32 | 8 years 4 months | Non-Hispanic white | Female | DORV | None | No | No | No but had stroke | Abnormal platelet dysfunction | No | No | No | No | None |
| 33 | 8 years, 5 months | Non-Hispanic white | Male | HLHS | None | No | No | Gross motor delay | Failure to thrive needing g-tube now s/p removal, hypotonia, mild penile torsion | No | No | No | No | None |
| 34 | 8 years, 5 months | Non-Hispanic white | Male | HLHS | 1 month | No | Yes | GDD | Chronic neutropenia; hypotonia; needed g-tube and nissen for vomiting | No | Yes (2013) | Inherited Neutropenia Gene Sequencing Panel- heterozygous c.1037C>T  (p.Pro346Leu) VUS in *WIPF1*  Reanalyzed- Likely benign | No | None |
| 35 | 8 years, 5 months | Non-Hispanic white | Male | Tricuspid Atresia | 2 months | No | Yes | GDD, learning difficulties, ADHD | No | No | Yes (2013) | No | No | None- told not to follow up unless there are concerns |
| 36 | 8 years, 6 months | Non-Hispanic white | Male | HLHS | 2 week | No | Yes | Learning difficulties, ADHD, IQ of 72, speech and language delay and fine motor delay | No | No | No- F.D. | No | No | None- deferred genetic testing |
| 37 | 8 years, 7 months | Non-Hispanic white | Male | Pulmonary Atresia, Tricuspid Atresia | None | No | No | Yes due to stroke | Seizures and watershed strokes after Fontan | No | No | No | No | None |
| 38 | 8 years, 9 months | Non-Hispanic white | Male | D-TGA/VSD with RV hypoplasia/coarctation | 1 day old | Yes | Yes | IQ 49; ADHD; gross motor delay | No | No | Yes (2012) | Heterotaxy panel (2012)  4 genes | No | None- told not to follow up unless there are concerns |
| 39 | 8 years, 9 months | Non-Hispanic white | Female | HLHS | 7.5 year old (CICU stay wasn't at CCHMC) | Yes | Yes | Moderate ID; IQ of 69 | Caudate stroke, advanced bone age, nocturnal enuresis, premature adrenache, ADHD, PTSD, GAD (No heterotaxy) | No | Yes (2019) | Autism/ID (2019) with *CDH2* (c.2629\_2630delAG p.Ser877Stop) VUS  Reanalyzed and likely pathogenic  Heterotaxy panel- *ZIC3* heterozygous VUS (don’t have report) | No | None |
| 40 | 9 years, 2 months | Non-Hispanic white | Male | HLHS | None | No | No | No; IQ 121 | Needed g tube for a while but now all oral fed | No | No | No | No | None |
| 41 | 9 years, 5 months | Hispanic | Male | HLHS | None | No | No | Learning difficulties, ADHD, IQ 73, | Tracheomalacia s/p tracheostomy which is now closed, and g-tube which has since been removed | No | No | No | No | None |
| 42 | 9 years, 5 months | Non-Hispanic white | Female | Hypoplastic left heart syndrome | None | No | No | No | No | No | No | No | No | None |
| 43 | 9 years, 5 months | Non-Hispanic white | Female | Shone's complex | 10 months | Yes | Yes | GDD, moderate ID, IQ 46 | Microcephaly, broad distal tufts of her terminal phalanges (fingers), her very short midphalanx of the 5th fingers and clinodactyly bilaterally, and the rounded appearance of her iliac crest, hyperinsulin hypoglycemia | Yes (2012) | Yes (2012) | Hyperinsulinism panel | No | None- family did not want to be seen |
| 44 | 9 years, 6 months | Non-Hispanic white | Male | Tricuspid atresia | 1 month | No | Yes | GDD | Hypotonia, trach and vent, g-tube, macular chorioretinal scar of right eye, astigmatism, nystagmus, HIE, Kyphoscoliosis | No | Yes (2012) | No | No | None |
| 45 | 9 years, 7 months | Hispanic | Female | Ebstein anomaly | 2 week | Yes | Yes | GDD, mild intellectual disability | Dysphagia needing g-tube | No | Yes (2011) | No | No | Seen one time |
| 46 | 9 years, 7 months | Non-Hispanic white | Male | HLHS | None | No | No | GDD. On track for learning | None | No | No | No | No | None |
| 47 | 9 years, 7 months | Non-Hispanic white | Male | HLHS | 2 months | Yes | Yes | GDD; IQ 106 | Mild dysmorphic features (hyperteloric, posteriorly rotated and low set ears, low nasal bridge with anteverted nares, mouth downturned, widely spaced nipples, clinodactyly, blue sclerae) post-natal growth restriction, hydrocele | No | Yes (2011) | Noonan Syndrome and, Glucose-6-Phosphate Dehydrogenase Deficiency Analysis (2012) | Ordered but denied in 2013 | Seen one time |
| 48 | 9 years, 7 months | Non-Hispanic white | Female | HLHS | 2 weeks | No | Yes | No | None | No | No- F.D. | No | No | None |

ADHD: Attention Deficit and Hyperactivity Disorder; ASD: Atrioseptal Defect; AV: Atrioventricular; CHD: Congenital Heart Disease; CSA: Central Sleep Apnea; DORV: Double Outlet Right Ventricle; F.D.: Family Declined; GC: Genetic Counselor; GDD: Global Developmental Delay; HLHS: Hypoplastic Left Heart Syndrome; ID: Intellectual Disability; IQ: Intelligent Quotient; NDD: Neurodevelopmental Disorder; OSA: Obstructive Sleep Apnea; PA: Pulmonary Artery Atresia; TAPVR: Total anomalous pulmonary venous return; TGA: Transposition of Great Arteries; VSD: Ventricular Septal Defect

For testing, if it states the box states yes but does not have a result, it means that the testing was negative.