

Not Started **Demographics Form**[Print this Form](#)**1. Birth Country**

- AFG (Afghanistan)
 LUX (Luxembourg)
- ALA (Åland Islands)
 MAC (China, Macao Special Administrative Region)
- ALB (Albania)
 MDG (Madagascar)
- DZA (Algeria)
 MWI (Malawi)
- ASM (American Samoa)
 MYS (Malaysia)
- AND (Andorra)
 MDV (Maldives)
- AGO (Angola)
 MLI (Mali)
- AIA (Anguilla)
 MLT (Malta)
- ATG (Antigua and Barbuda)
 MHL (Marshall Islands)
- ARG (Argentina)
 MTQ (Martinique)
- ARM (Armenia)
 MRT (Mauritania)
- ABW (Aruba)
 MUS (Mauritius)
- AUS (Australia)
 MYT (Mayotte)
- AUT (Austria)
 MEX (Mexico)
- AZE (Azerbaijan)
 FSM (Micronesia, Federated States of)
- BHS (Bahamas)
 MCO (Monaco)
- BHR (Bahrain)
 MNG (Mongolia)
- BGD (Bangladesh)
 MNE (Montenegro)
- BRB (Barbados)
 MSR (Montserrat)
- BLR (Belarus)
 MAR (Morocco)
- BEL (Belgium)
 MOZ (Mozambique)
- BLZ (Belize)
 MMR (Myanmar)
- BEN (Benin)
 NAM (Namibia)
- BMU (Bermuda)
 NRU (Nauru)
- BTN (Bhutan)
 NPL (Nepal)
- BOL (Bolivia, Plurinational State of)
 NLD (Netherlands)
- BES (Bonaire, Saint Eustatius and Saba)
 NCL (New Caledonia)
- BIH (Bosnia and Herzegovina)
 NZL (New Zealand)
- BWA (Botswana)
 NIC (Nicaragua)
- BRA (Brazil)
 NER (Niger)
- VGB (British Virgin Islands)
 NGA (Nigeria)
- BRN (Brunei Darussalam)
 NIU (Niue)
- BGR (Bulgaria)
 NFK (Norfolk Island)
- BFA (Burkina Faso)
 MNP (Northern Mariana Islands)
- BDI (Burundi)
 NOR (Norway)
- KHM (Cambodia)
 PSE (Occupied Palestinian Territory)
- CMR (Cameroon)
 OMN (Oman)
- CAN (Canada)
 PAK (Pakistan)
- CPV (Cape Verde)
 PLW (Palau)
- CYM (Cayman Islands)
 PAN (Panama)
- CAF (Central African Republic)
 PNG (Papua New Guinea)
- TCD (Chad)
 PRY (Paraguay)
- CHL (Chile)
 PER (Peru)
- CHN (China)
 PHL (Philippines)
- COL (Colombia)
 PCN (Pitcairn)
- COM (Comoros)
 POL (Poland)
- COG (Congo)
 PRT (Portugal)
- COK (Cook Islands)
 PRI (Puerto Rico)
- CRI (Costa Rica)
 QAT (Qatar)
- CIV (Côte d'Ivoire)

- HRV (Croatia)
- CUB (Cuba)
- CUW (Curaçao)
- CYP (Cyprus)
- CZE (Czech Republic)
- PRK (Democratic People's Republic of Korea)
- COD (Democratic Republic of the Congo)
- DNK (Denmark)
- DJI (Djibouti)
- DMA (Dominica)
- DOM (Dominican Republic)
- ECU (Ecuador)
- EGY (Egypt)
- SLV (El Salvador)
- GNQ (Equatorial Guinea)
- ERI (Eritrea)
- EST (Estonia)
- ETH (Ethiopia)
- FRO (Faeroe Islands)
- FLK (Falkland Islands, Malvinas)
- FJI (Fiji)
- FIN (Finland)
- FRA (France)
- GUF (French Guiana)
- PYF (French Polynesia)
- GAB (Gabon)
- GMB (Gambia)
- GEO (Georgia)
- DEU (Germany)
- GHA (Ghana)
- GIB (Gibraltar)
- GRC (Greece)
- GRL (Greenland)
- GRD (Grenada)
- GLP (Guadeloupe)
- GUM (Guam)
- GTM (Guatemala)
- (GGY) Guernsey
- GIN (Guinea)
- GNB (Guinea-Bissau)
- GUY (Guyana)
- HTI (Haiti)
- VAT (Holy See)
- HND (Honduras)
- HKG (China, Hong Kong Special)
- HUN (Hungary)
- ISL (Iceland)
- IND (India)
- IDN (Indonesia)
- IRN (Iran, Islamic Republic of)
- IRQ (Iraq)
- IRL (Ireland)
- IMN (Isle of Man)
- ISR (Israel)
- ITA (Italy)
- JAM (Jamaica)
- JPN (Japan)
- JEY (Jersey)
- KOR (Republic of Korea)
- MDA (Republic of Moldova)
- REU (Réunion)
- ROU (Romania)
- RUS (Russian Federation)
- RWA (Rwanda)
- SHN (Saint Helena)
- KNA (Saint Kitts and Nevis)
- LCA (Saint Lucia)
- SPM (Saint Pierre and Miquelon)
- VCT (Saint Vincent and the Grenadines)
- BLM (Saint-Barthélemy)
- MAF (Saint-Martin, French Part)
- WSM (Samoa)
- SMR (San Marino)
- STP (Sao Tome and Principe)
- SAU (Saudi Arabia)
- SEN (Senegal)
- SRB (Serbia)
- SYC (Seychelles)
- SLE (Sierra Leone)
- SGP (Singapore)
- SXM (Sint Maarten, Dutch Part)
- SVK (Slovakia)
- SVN (Slovenia)
- SLB (Solomon Islands)
- SOM (Somalia)
- ZAF (South Africa)
- SSD (South Sudan)
- ESP (Spain)
- LKA (Sri Lanka)
- SDN (Sudan)
- SUR (Suriname)
- SJM (Svalbard and Jan Mayen Islands)
- SWZ (Swaziland)
- SWE (Sweden)
- CHE (Switzerland)
- SYR (Syrian Arab Republic)
- TJK (Tajikistan)
- THA (Thailand)
- MKD (The Former Yugoslav Republic of Macedonia)
- TLS (Timor-Leste)
- TGO (Togo)
- TKL (Tokelau)
- TON (Tonga)
- TTO (Trinidad and Tobago)
- TUN (Tunisia)
- TUR (Turkey)
- TKM (Turkmenistan)
- TCA (Turks and Caicos Islands)
- TUV (Tuvalu)
- UGA (Uganda)
- UKR (Ukraine)
- ARE (United Arab Emirates)
- GBR (United Kingdom of)
- TZA (United Republic of Tanzania)
- USA (United States of America)
- VIR (United States Virgin Islands)

- JOR (Jordan)
- KAZ (Kazakhstan)
- KEN (Kenya)
- KIR (Kiribati)
- KWT (Kuwait)
- KGZ (Kyrgyzstan)
- LAO (Lao, People's Democratic Republic)
- LVA (Latvia)
- LBN (Lebanon)
- LSO (Lesotho)
- LBR (Liberia)
- LBY (Libya)
- LIE (Liechtenstein)
- URY (Uruguay)
- UZB (Uzbekistan)
- VUT (Vanuatu)
- VEN (Venezuela, Bolivarian Republic of)
- VNM (Vietnam)
- WLF (Wallis and Futuna Islands)
- ESH (Western Sahara)
- YEM (Yemen)
- ZMB (Zambia)
- ZWE (Zimbabwe)
- OTH (Other, specify)
- Unknown

2. Premature Birth Yes
 Indicate whether the patient was born prematurely as defined by No
 a gestational period of less than or equal to 37 weeks. Unknown

3. Race African-American (Black)
 Alaska Indian
 American Indian
 Asian
 Caribbean
 Eskimo
 Hispanic/Latino
 Mixed race
 Pacific Islander
 White
 Other, specify

 Unknown

4. Did patient have any non-cardiac congenital anatomic abnormalities? Yes
 No
 Unknown

4a. Non-cardiac congenital anatomic abnormalities Major abnormality craniofacial
 Major abnormality of brain
 Major abnormality of spine and spinal cord
 Major abnormality of larynx - trachea - or bronchus
 Major abnormality of lung
 Major abnormality of abdominal wall
 Major abnormality of diaphragm
 Major abnormality of biliary system
 Major abnormality of gastrointestinal system
 Major abnormality of gastrointestinal system, Necrotizing enterocolitis
 Major abnormality of kidney - ureter - or bladder

0 option(s) selected

- 5. Was patient diagnosed with a chromosomal abnormality?**
- Yes
 No
 Unknown

5a. Chromosomal abnormality

Check all that apply.

0 option(s) selected

- | | |
|--|--------------------------------------|
| <input type="checkbox"/> 11p15.5 | <input type="checkbox"/> 5p |
| <input type="checkbox"/> 11q | <input type="checkbox"/> 6p12 |
| <input type="checkbox"/> 12p1.21 | <input type="checkbox"/> 7q11 |
| <input type="checkbox"/> 12p12.1 | <input type="checkbox"/> 7q11.23 |
| <input type="checkbox"/> 12q24 | <input type="checkbox"/> 7q32 |
| <input type="checkbox"/> 15q21.1 | <input type="checkbox"/> 7q34 |
| <input type="checkbox"/> 1q42.1 | <input type="checkbox"/> 8q12 |
| <input type="checkbox"/> 20p12 | <input type="checkbox"/> TGFBR1 or 2 |
| <input type="checkbox"/> 22q11deletion | <input type="checkbox"/> Trisomy 08 |
| <input type="checkbox"/> 2p21 | <input type="checkbox"/> Trisomy 09 |
| <input type="checkbox"/> 3p22 | <input type="checkbox"/> Trisomy 13 |
| <input type="checkbox"/> 45X0 | <input type="checkbox"/> Trisomy 18 |
| <input type="checkbox"/> 47,XXY | <input type="checkbox"/> Trisomy 21 |
| <input type="checkbox"/> 4p | <input type="checkbox"/> Other |
| <input type="checkbox"/> 4p16 | |

- 6. Was the patient diagnosed with a syndrome?**
- Yes
 No
 Unknown

6a. Syndromes

0 option(s) selected

- | | |
|---|--|
| <input type="checkbox"/> Alagille syndrome (intrahepatic biliary duct agenesis) | <input type="checkbox"/> Kartagener syndrome (Siewert syndrome) (Primary ciliary dyskinesia) |
| <input type="checkbox"/> Apert Syndrome | <input type="checkbox"/> Klinefelter syndrome (XXY Syndrome) |
| <input type="checkbox"/> Brugada syndrome | <input type="checkbox"/> LEOPARD syndrome |
| <input type="checkbox"/> Cardiofaciocutaneous Syndrome | <input type="checkbox"/> Loeys-Dietz syndrome |
| <input type="checkbox"/> Carpenter Syndrome | <input type="checkbox"/> Long QT syndrome |
| <input type="checkbox"/> Cat-eye Syndrome | <input type="checkbox"/> Marfan syndrome (15q21,1) |
| <input type="checkbox"/> CHARGE Association | <input type="checkbox"/> Mucopolysaccharidosis |
| <input type="checkbox"/> Cornelia de Lange syndrome | <input type="checkbox"/> Noonan syndrome |
| <input type="checkbox"/> Cri-du-chat syndrome | <input type="checkbox"/> Patau syndrome (Trisomy 13) |
| <input type="checkbox"/> Deletion 10 p syndrome | <input type="checkbox"/> Pierre Robin syndrome |
| <input type="checkbox"/> Deletion 8 p syndrome | <input type="checkbox"/> Prune Belly Syndrome |
| <input type="checkbox"/> DiGeorge syndrome (velocardiofacial syndrome) (conotruncal anomaly face syndrome) (22q11 deletion) | <input type="checkbox"/> Rethore Syndrome (Trisomy 9) |
| <input type="checkbox"/> Down syndrome (Trisomy 21) | <input type="checkbox"/> Fetal Rubella syndrome (Congenital rubella syndrome) |
| <input type="checkbox"/> Edwards syndrome (Trisomy 18) | <input type="checkbox"/> Rubinstein-Taybi Syndrome |
| <input type="checkbox"/> Ehlers- Danlos Syndrome | <input type="checkbox"/> Short QT Syndrome |
| <input type="checkbox"/> Ellis-van Creveld syndrome | <input type="checkbox"/> Sickle cell disease |
| <input type="checkbox"/> Fetal alcohol syndrome (FAS) | <input type="checkbox"/> Sickle cell trait |
| <input type="checkbox"/> Fetal drug exposure | <input type="checkbox"/> Smith-Lemli-Opitz syndrome |

- | | |
|--|--|
| <input type="checkbox"/> Goldenhar syndrome | <input type="checkbox"/> Turner syndrome (45XO) |
| <input type="checkbox"/> Heterotaxy syndrome | <input type="checkbox"/> VACTERL syndrome (VACTER/VATER/VATERR syndrome) |
| <input type="checkbox"/> Heterotaxy syndrome, Asplenia syndrome | <input type="checkbox"/> Von Willebrand disease (vWD) |
| <input type="checkbox"/> Heterotaxy syndrome, Polysplenia syndrome | <input type="checkbox"/> Williams syndrome (Williams-Beuren syndrome) (7q11/7q11.23) |
| <input type="checkbox"/> Holt-Oram syndrome | <input type="checkbox"/> Wolff-Parkinson-White syndrome (WPW syndrome) |
| <input type="checkbox"/> Jacobsen Syndrome | <input type="checkbox"/> Wolf-Hirschhorn syndrome |
| <input type="checkbox"/> Kabuki syndrome | <input type="checkbox"/> Other Syndrome |

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