### About the DSR & its Membership
The Donor Sibling Registry (DSR) is a non-profit, worldwide organization dedicated to educating, connecting and supporting donors, recipients and offspring. More than 26,000 members, the DSR has helped to connect more than 7,000 half siblings and donors with each other. The DSR doesn’t just generate genetically related joy—it also shines light on serious genetic concerns about donor conception. Frequently, the DSR counsels recipients whose children have inherited undisclosed genetic disorders, or who have discovered that their donor was dishonest regarding health, or that the sperm bank didn’t notify them about a reported illness. US donors can father many offspring (at least one US donor is known to have fathered more than 125 offspring, so far) so a greater number of people will be at risk from a single person’s genetic makeup.

### Sources of Information
Medical and genetic information compiled from surveys, direct reporting to the DSR, and as reported by Cabiri DNA testing.

**2008 Survey-155 Egg Donors**
- 94% of donors have medical/genetic issues reported by their clinic(s) for medical updates.
- 96% of egg donors have never been contacted by their clinic(s) for medical updates.
- 84% of sperm donors have never been contacted by their clinic(s) for medical updates.

**2009 Survey- 163 Sperm Donors**
- 96% of sperm donors have never been contacted by their clinic(s) for medical updates.
- 23% of sperm donors felt that they had medical/genetic issues that would be important to share with families.
- 31% of egg donors felt they had medical/genetic issues that would be important to share with families.
- 94% of sperm donors would have accepted an offer for genetic testing, had it been offered by their sperm banks.

**2009 Survey- 790 Donor Offspring**
- 10% of donor offspring who wish to make contact with their donors list learning more about their medical background as a main reason for the desired contact.

### Privately Reported Health & Genetic Issues from Donors
Medical and genetic issues reported by sperm and egg donors for themselves or their immediate family include:
- Albinism, Alcoholism, Aspergers, Autism, Bi-Polar Disorder, Brain Aneurysm, Breast Cancer, CF Carrier, Caravan Disease, Cavernous Angioma, Colon Cancer, Congenital Heart Disease, Hashimoto’s Syndrome, Hemachromatosis, High Blood Pressure Leading to Stroke, Leukemia, Lung Cancer, Melanoma, Multiple Myeloma, Multiple Sclerosis, Polycystic Kidney Disease, Prostate Cancer, Rheumatoid Arthritis, Spinal Muscular Atrophy, Type II Diabetes, Ulcerative Colitis.

### Privately Reported Health & Genetic Issues from Recipients and Offspring
Acute Lymphoblastic Leukemia, ADHD, ADD, Alcoholism, Amniotic Band Syndrome, Aspergers, Asthma, Atrial Septal Defect, Auto Immune Thyroiditis, Bi-Polar Disease, Brachied-Chain Ketoaciduria, Complex Congenital Heart Defect, Congenital Heart Disease, Congenital Hypothyroidism, Cystic Fibrosis, Dwan Syndrome, Ebstein’s Anomaly, Ectodermal Dysplasia, Heart Murmur, Hemoglobin D, Hemorrhagic Lymphohistoipoiesis, Hole in Heart, Horseshoe Kidney, Hydrocephalus, Hypertrophic Cardiomyopathy, Hypophosphatasa, Hypoplasia, Imperforated Anus, Juvenile Dermatomyositis, Juvenile Arthritis, Katanosis Pilaris, Kidney Disease, Lethal Dwarfing Syndrome, Marfar’s Syndrome, Medium Chain CoA Dehydrogenase Deficiency (MCADD), Metabolic Genetic Disorder, Mitral Valve Stenosis, Multiple Hereditary Exostoses, PANDAS, PHACES Syndrome, Phenylketonuria (PKU), Polycystic Kidney Disease, Prader-Willi, Rasmussen’s Encephalitis, Renal Disease, Retinoblastoma, Seizure Disorders, Severe Congenital Neutropenia, Spinal Muscular Atrophy, Tay Sachs, Tourettes, Tracheo-Eosophageal Fistula, Truncus Arteriosus, Type I Diabetes, Van Der Woude Syndrome, Vesicoureteral Reflux, Von Willebrand Disease, William-Beuren Syndrome, Zellweger Syndrome.

See Attachment for additional newly reported genetic and medical issues.

### Offspring Who Desire Contact with Donors for Genetic/Medical Information
74% of donor offspring who wish to make contact with their donors list learning more about their medical background as a main reason for the desired contact.

### Publicly Reported Health & Genetic Issues
- **2009:** London Women’s Clinic used chromosomally abnormal donor sperm to treat 11 women including a couple who had to destroy 22 embryos created over a year of treatment. The Independent and BioNews.
- **2008:** A child conceived using gametes from anonymous sperm and ova donors was diagnosed with spinal muscular atrophy type 1. Fertility and Sterility.
- **2009:** New England Cryogenic sued by a woman claiming that her children inherited genetic disorders. Other families who used this donor also report issues. Boston Herald.
- **2009:** A Pacific Reproductive Services donor passed along HCM, a fatal heart disease to 9 of his 22 known offspring. One child consequently died. J Am Med Assn.
- **2008:** Two donor sibling cohorts from California Cryobank have a very high percentage of their children diagnosed with PSD-NS (Autism). O Mag.
- **2006:** An International Cryogenic donors transmit Severe Congenital Neutropenia to at least 5 offspring. J Pediatrics.
- **2006:** A Fairfax donor offspring diagnosed with Delta Storage Pool Deficiency (delta-SPD). SELF Mag.
- **2004:** A Fairfax donor transmitted familial Hemophagocytic Lymphohistiocytosis (FLH) to twins; one child subsequently died. SELF Mag.
- **2001:** British based donor of Australian origin with at least 43 offspring, passed along potentially fatal genetic disorder—Optic Syndrome. Sunday Times.

### Current Practices & Regulation
In the US, FDA oversight has been directed at the prevention of infectious diseases including STD’s. Little attention has been paid to the potential transmission of genetic diseases. (US & UK requirements are similar.)

**Current US Screening:**
- Sexually Transmitted Diseases: HIV, HTLV, Hepatitis B & C, Syphilis, Gonorrhea, Chlamydia, CMV
- Genetic testing varies significantly at US clinics as adhering to ASRM recommendations is voluntary. The less screening carried out, the fewer donors need be disqualified. Fewer tests also equals less cost.

Some clinics and sperm banks test for some of the following:

#### Current US Genetic Testing (Select Groups only):
- Cystic Fibrosis, Sickle-Cell Disease, Tay Sachs, Caravan Disease, Gauchers Disease, Niemann-Pick’s Disease, B-Thalassemia.

#### Recommended Medical & Genetic Testing
**Testing for All donors:** Karyotyping. Cystic Fibrosis, Tay Sachs, Fragile X, Hemachromatosis (for HFE mutation), BRCA 1 & 2, Celiac Disease, Polyposis Conditions Caused by Mutations in the APC Gene, Hereditary Non-Polyposis Colorectal Cancer (HNPCC), Glycogen Storage Diseases such as Fabry’s and Niemann-Pick, Polycystic Disease, Huntington’s Disease, Melanoma (CDKN2A Gene) and Moya-Moya. Martin’s testing for donors over 62.

**Additionally:** More thorough physical examinations including organ function, a face-to-face medical history intake and full psychological screening.

### Other Recommendations
- **Periodic donor quarantine using the “5&2” protocol. A donor would be permitted no more than 5 pregnancies. They would then be quarantined until the youngest reached age two and completed an extensive pediatric evaluation, along with the other 4 half siblings.**
- **Track all recipients, donors and births.**
- **Mandatory reporting of all live births from each donor.**
- **Limit the number of births conceived by any one donor.**
- **Require donors to regularly update their family medical history and have this information available to all families who have used this donor.**
- **Encourage donors, parents and offspring to share and update medical and genetic information with each other.**
- **Require legal and financial protection for all donors so that they may feel safe to update and report medical issues.**
- **Consequences for donors who knowingly withhold important medical and genetic information from clinics.**
- **Counsel parents on openness, full disclosure and the importance of using open donors.** Emphasize the importance of people having information about their genetic, ancestral and medical backgrounds. Counsel all donors on the same.
- **Initiate follow-up health history reporting of egg donors.**
Additional Genetic and Medical Issues (not known to be present in recipient’s family) reported in Donor Sibling Registry Surveys for Parents and privately reported:

- Agenesis of the Corpus Callosum
- Alpha Thalassemia Trait
- Arnold-Chiari malformation
- Bicuspid Aortic Valve Disease
- Borderline Personality Disorder
- Cardiac (ASD PDA) and Pulmonary Hypertension
- Cerebral Palsy
- Chromosome abnormality: 5p minus or Cri-du-chat.
- Coarctation of Aorta
- Congenital Lobar Emphysema
- Cornelia de Lange Syndrome
- Cystic Hygroma
- Depression
- Dysgraphia
- Eosinophilic Esophagitis
- Epilepsy
- Febrile Seizures
- Femoral Antversion
- Fragile X
- Genetic High Cholesterol
- Graves Disease
- Hydrocephalus
- Hypotonia
- Ileal Atresia
- Kidney Reflux Stage 3
- Kleinfelter’s Syndrome
- Langerhans Cell Histiocytosis
- Leukemia
- Marcus Gunn Syndrome
- Medulloblastoma Brain Tumor
- MTHFR C677T gene mutation
- Myelomeningocele (Spina bifida)
- Neoblastoma Stage 3
- Neurofibromatosis Type 1
- NUT Midline Carcinoma
- Oppositional Defiant Disorder
- PCOS
- PDD-NOS
- Pectus Excavatum
- Plagiocephaly
- Pyloric Stenosis
- Primary Sclerosing Cholangitis
- Radioulnar Synostosis
- Rett Syndrome
- Robersonian Translocation Chromosome
- Rotary Nystagmus
- Reiters Syndrome
- SVT- Supraventricular Tachycardia
- Sagittal Craniosynostosis
- Scoliosis
- Sensory Integration Dysfunction
- Sickle Cell Carrier
- Sieves Disease
- Spastic Quad Cerebral Palsy
- Strabismus
- Sub-Aortic Membrane
- Tethered Spinal Cord Syndrome
- Thyroid Cancer
- Torticollis
- VACTERL Association
- Vasovagal Syncope
- Vesico-Uretal Reflux
- Wilm’s Tumor (Kidney Cancer)
- Wolff-Parkinson-White Syndrome