The Case for Comprehensive Medical and Genetic Testing of Gamete Donors
Donor Sibling Registry

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. With more than 29,800 members, the DSR has helped to connect more than 8,100 half siblings and/or donors with each other. The DSR doesn’t just generate genetically related ‘jy-ta’ it also shines light on serious genetic concerns about gamete donation. 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 Cabri DNA testing.

2008 Survey - 155 Egg Donors
2009-Survey - 164 Sperm Donors
2009 Survey - 759 Donor Offspring
2009 Survey – 1700 Sperm Donor Recipients

Medical Update Requests from Clinics and Sperm Banks, Donors with Medical and Genetic Issues to Share, Sperm Donors Would Accept Genetic Testing
Currently, many US facilities either refuse to update donor/offspring medical information, or even if they accept updates, refuse to share the information, or make the process of reporting so complex and expensive that donors and recipients simply cannot comply or afford it. In addition, US sperm banks do not have an accurate accounting of all children born from any one donor, so if illness is reported, it is then impossible to notify all relevant families.

84% of sperm donors have never been contacted by their clinic(s) for medical updates.
96% of egg 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 had been offered by their sperm banks.

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, Colonic Cancer, Congential Heart Disease, Hashimoto’s Syndrome, Hemachromatosis, High Blood Pressure Leading to Stroke, Leukemia, Lung Cancer, Melanoma, Mitral Valve Prolapse, 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, ADD, ADHD, Alzheimer, Amyotrophic Lateral Sclerosis, Aspergers, Asthma, Atiral Septal Defect, Auto Immune Thyroiditis, Bi-Polar Disorder, Brachian-branch Katoaciduria, Complex Congential Heart Defect, Congential Heart Disease, Congential Hypothyroidism, Cystic Fibrosis, Dwayne Syndrome, Elastoinen Arthritis, Eccodermal Dysplasia, Heart Murmure, Hemoglobin D, Hemophagocytic Lymphohistiocytosis, Hole in Heart, Horseshoe Kidney, Hydrocephalus, Hypertrophic Cardiomyopathy, Hypophysstasis, Hypoasopias, Imperforated Anus, Juvenile Dermatomyositis, Juvenile Arthritis, Karonos Phlanas, Kidney Disease, Lethal Dwarving Syndrome, Marfan’s Syndrome, Medium Chain Acyl CoA Dehydrogenase Deficiency (MCAD), 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 Congential Neupotenia, Spinal Muscular Atrophy, Tay Sachs, Tourettes, Tracheo-Eosophageal Fistula, Truncus Arteriosis, Type I Diabetes, Van Der Woude Syndrome, Vescouretural Reflux, Von Willebrand Disease, Williams-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
2011: At least nine children (Hordic Cryobank & California Cryobank) that have been conceived with the sperm of a man with a genetically inherited disorder Neurofibromatosis (NF1 or von Recklinghausen disease). Thelocal.com..
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.
2009: 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 Crogenic said by a woman claiming that her children inherited genetic disorders. Other families who used this donor also report issues. Boston Herald.
2008: Two donor sibling cohorts from California Cryobank have a very high percentage of their children diagnosed with PDD-NOS (Autism). O Mag.
2006: A Fairfax donor offspring diagnosed with Delta Storage Pool Deficiency (delta-SPD), SELF Mag.
2004: A Fairfax donor transmitted familial Hemagpoyctic Lymphohistioctosis (FH), to twins, one child subsequently died. SELF Mag.
2001: One recipient, two cases of spinal muscular atrophy (SMA), Fertility and Sterility
2001: British based donor of Australian origin with at least 43 offspring, passed along potentially fatal genetic disorder -Opitz Syndrome. London 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:
Cystic Fibrosis, Megaloblastic Anemia, Aerobic Resistance, Diabetes Mellitus, Down Syndrome, Early Childhood Asthma, Family History, Genitourinary Abnormalities, HIV/AIDS, Hypothyroidism, Hypertension, Hysterectomy, Internal Mitral Valve Prolapse, Klinefelter Syndrome, Leukemia, Luteinizing Hormone, Medium Chain Acyl CoA Dehydrogenase Deficiency (MCAD), 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 Congential Neupotenia, Spinal Muscular Atrophy, Tay Sachs, Tourettes, Tracheo-Eosophageal Fistula, Truncus Arteriosis, Type I Diabetes, Van Der Woude Syndrome, Vescouretural Reflux, Von Willebrand Disease, Williams-Beuren Syndrome, Zellweger Syndrome

*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 repor 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.

Other Recommendations

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*mandatory reporting of all live births from each donor.
*Limit the number of offspring that can be conceived for 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.

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

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2010

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 1 Deficiency
- Alpha Thalassemia Trait
- Apraxia
- Arnold-Chiari malformation
- Atrial Septal Defect (ACD)
- Bi-cuspid 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
- Craniosynostosis
- Cystic Hygroma
- Dandy Walker Variant
- Depression
- Down Syndrome
- Dysgraphia
- Eosinophilic Esophagitis
- Epilepsy
- Febrile Seizures
- Femoral Antversion
- Fragile X
- Genetic High Cholesterol
- Goldenhar Syndrome
- Graves Disease
- Hashimoto's disease (chronic lymphocytic thyroiditis)
- 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)
- Myotonic Muscular Dystrophy (MMD)
- Neublastoma Stage 3
- Neurofibromatosis Type 1
- NUT Midline Carcinoma

Oppositional Defiant Disorder
PCOS
PDD-NOS
Pectus Excavatum
Plagiocephaly
Pyloric Synostis
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
Third Degree Heart Block
Thyroid Cancer
Torticollis
Trachea Esophageal Fistula
Vacteral Association
Vasovagal Syncope
Vesico-Uretal Reflux
Wilms' Tumor (Kidney Cancer)
Wolff-Parkinson-White Syndrome
Zellweger Syndrome