"My family history caused me concern about passing HD on to my children. My husband and I thought carefully about it and we decided that any expense or discomfort experienced now is worth the opportunity to protect our children. I have the power to cure HD for the future generations of my family!"
-Stacy Brookhyser,
Huntington Beach, CA

"Pre-implantation genetic diagnosis gives couples whose offspring are at risk for certain genetic diseases an important new reproductive option. By using this technology, at-risk parents can avoid transmitting Huntington's disease to their children, and hence, to future generations."

-Ann Walker, genetic counselor,
UC Irvine

For more information:

Please visit:
www.HDFreeWithPGD.com
Or Email:
info@HDFreeWithPGD.com

Visit the Orange County, CA
Huntington's Disease Clinic:

Gottschalk Medical Plaza
UC Irvine
4th Friday of every month

Call 949-824-1264
for more information

Developed with:

The Huntington's Disease Program of the University of California, Irvine

HD Free With PGD!

Planning a Huntington's Disease-free family with In-Vitro Fertilization (IVF) and Pre–Implantation Genetic Diagnosis (PGD)

With the help of skilled medical professionals, YOU have the ability to prevent your children from inheriting HD.

This helpful guide will give you the information you need to begin the process.

What is PGD?

After *in-vitro* fertilization (IVF), embryos can be tested using pre-implantation genetic diagnosis (PGD) to determine their genetic makeup. When the embryos contain eight cells, they are tested for the HD mutation in the Huntingtin gene. Only embryos with the unaffected gene are transferred to the mother. These embryos will never get HD or transmit it to their children. The procedure essentially eliminates HD from that family line. Forever.

Who is it for?

PGD is useful for couples who are at risk for passing a genetic disorder to their children. Because the HD mutation is dominant, a parent who carries it has a 50:50 chance to pass it to each of his or her children – even if they do not yet have symptoms. People who want to stop HD from being passed on to their family line may want to consider PGD.

Do I have to be tested for HD before doing the PGD procedure?

No. It is possible to have "non-disclosing" PGD. The doctor will transfer only unaffected embryos, but won't tell you if any embryos actually carried the mutation. You can then be assured that your child won't inherit HD without learning your own status.

What are the steps involved?

After you have found a good fertility specialist, you will be asked for a small blood sample to help with the diagnosis. You will also be asked for samples from other family members, if possible. The laboratory will analyze the DNA sample for the HD mutation and prepare a test for the tiny, delicate embryos. This can take up to 8 weeks.

When the test is ready, the doctor will ask you to undergo a few procedures, which may include blood screening, semen analysis and ultrasound. Next, the female partner will take a series of injections to stimulate a number of eggs. After a few weeks, the eggs are retrieved and they are fertilized with her partner's sperm. After the embryos have divided to the eight-cell stage, one cell is carefully removed and sent to the lab to be tested for the HD gene.

After the laboratory has finished testing the embryos for HD, the doctor transfers one or more of the HD-free embryos back into the mother's uterus. Hopefully at least one will implant and result in a healthy baby! Occasionally if pregnancy doesn't result, it may be necessary to repeat the process.

How much money does it cost?

IVF with PGD usually costs between $9,000 and $18,000. The cost depends on the fertility specialist you select and his or her fees. At first glance, this looks like a lot of money. But compared with the lifelong emotional toll of wondering whether your child has HD, and possibly compared with care expenses associated with HD, this is a relatively small burden to bear.

Will my medical insurance cover the costs?

Possibly. Some states require that medical insurance plans cover IVF. Others leave it up to the plan. But even when a plan does not usually cover IVF, it may be possible to get some coverage due to an existing condition (i.e. being genetically predisposed to HD). If your insurance company considers IVF/PGD medically necessary, it may help with some or all of the cost.

Can PGD ensure that my children will NOT inherit HD?

Yes, and also your grandchildren and your other future descendents! When the doctor implants only embryos without the HD mutation, it stops the disease in your family. PGD is the only effective way we have to stop HD.