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Huntington's Disease Society of America

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Overview of Stem Cells in **HD Research and Development**

By George Yohrling, PhD; HDSA Director of Medical and Scientific Affairs

One of the main goals of the five year HDSA Strategic Plan is to support HD research and communicate its impact. In an effort to improve our research communication activities,HDSA recently launched a new HD Research Webinar Series. These monthly webinars will provide a regular forum for people with HD, families and caregivers to hear updates on the latest research findings directly from HD scientists.

Stem cells are an area of research that has received a lot of attention lately from both researchers and the community. To address this, we invited Dr. Jamshid Arjomand from CHDI Foundation to be the first presenter in the research webinar series. Dr. Arjomand is the Director of Basic Research at CHDI, where he oversees a large portfolio of HD stem cell-related research activities. Dr. Arjomand presented on the use of stem cells in HD research and therapeutics.

Stem cells are unspecialized cells capable of continuous renewal and capacity to become any cell type or organ. There are several varieties of stem cells which were briefly discussed. One type of stem cell that holds great promise is the induced pluripotent stem cell (iPSCs). These cells were described by Yamanaka et al in 2006, when his group discovered a way to reprogram adult skin into stem cells. This "revolutionary" finding resulted in Dr. Yamanaka being awarded the 2012 Nobel Prize for Physiology and Medicine.

Several different approaches to stem cell transplantation therapies were highlighted by Dr. Arjomand. The approach currently being tested, in small clinical studies, involves fetal brain transplant, in which small dissections of the developing fetal brain(s) are implanted into the regions most affected in HD, with the hope that the fetal graft will replace the dying HD striatal neurons. The largest such study is the ongoing clinical trial called Multicentric Intracerebral Grafting in Huntington's Disease (MIG-HD) being performed in France.The primary completion date of this trial is slated for mid-2013. Mesenchymal stem cells (MSCs) are another experimental option and their potential is only now being realized though basic mouse and rat studies. MSCs are predominantly derived from the bone marrow and seem to have a much more limited differentiation capacity, are thus referred to as "multipotent". Several different animal studies injected MSCs directly into the brain of HD rodent models and demonstrated potential in mediating some aspects of neuronal repair. Another approach capitalizes on the endogenous adult stem cells found in each of our brains. Although only tested in mice, the strategy is to coerce these cells to multiply, migrate and mature. However, these new neurons would still carry the mutation that is responsible for HD, so the long-term benefits of such an approach would need to be evaluated carefully. Finally, iPSCs can be created from a person with HD and the expanded huntingtin mutation can be corrected in a cell culture dish. In theory, these corrected cells could then be differentiated into striatal neurons and implanted into the brains of the same person with HD. However, this strategy is, at this time, only theoretical and many technical hurdles still need to be resolved before any clinical implementation could be considered.

While all very exciting possibilities, there are many questions that must be carefully addressed to ensure that stem cell treatment is safe and effective. Animal studies to understand the "what, where and how" of the different technologies must be conducted. These unknowns do not stop some from advertizing stem cells as a miracle treatment for a wide array of diseases. To address this troubling trend, the International Society for Stem Cell Research has created a website **(www.closerlookatstemcells.org**) that allows the public to better evaluate the claims made by some clinics offering treatment or soliciting trial participants. It also details 10 important points all people should know about stem cell treatments.

Finally, the potential use of stem cells in HD research and development was discussed. A large consortium of stem cell/HD researchers was formed in 2010 to spearhead this effort. This group is primarily funded by NINDS and CHDI, but other organizations, such as HDSA and HDF are also financially supporting these research efforts. The goal of the HD iPSC Consortium is not to develop a cell therapy for HD, but instead is focused on developing better and more relevant neuronal models of Huntington's disease for basic research, target identification & validation and drug discovery efforts. The Consortium will also develop a repository of well characterized HD stem cells and protocols that will be made available to the entire HD research community.

If you would like more information on stem cells, the NIH has created a helpful online resource at: **stemcells.nih.gov/info**

HDSA Information

Research Webinar

If you are interested in viewing Dr. Arjomand's webinar on stem cells or to register for future webinars, please visit **www.hdsa.org/researchwebinar.**

Caregiver's Corner

The next Caregiver's Corner webinar will take place on Thursday, March 28 at 12pm EST. Join HDSA for a special webinar presented by the Social Security Administration about applying for Disability for Huntington's disease. Sign up to participate at **www.hdsa.org/ccorner** and please share this information with others!

Educational Events

April 7

Long Island, NY

April 27

Waukesha, WI

April 27

Austin, TX

May 25

Glendale, AZ

Learn more at **www.hdsa.org/events**

We Are HDSA!

Like *We Are HDSA!*? Then sign up to receive it by e-mail! Send an e-mail to Seth J. Meyer at **smeyer@hdsa.org** with your e-mail address and ask to be added to the *We Are HDSA!* e-mail list today. Past issues of *We Are HDSA!* can be found on the HDSA website.

HDSA E-mail List

Want to get more information about HDSA events and activities? Visit the HDSA website at **www.hdsa.org** to sign up!

SPECIAL NEEDS Trusts

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Special Needs Trusts ("SNTs") are designed to help preserve the assets of people with disabilities without endangering their eligibility to receive public benefits.

People with disabilities who have more than a certain amount of available assets (the amount varies by state and the individual's marital status) are not eligible to receive public benefits such as Medicaid and Supplemental Security Income (SSI). Disabled individuals who have available assets in excess of the applicable amount ("the Asset Limit") must often deplete their assets to the requisite level before they qualify to receive public benefits.

As an alternative, the federal statutes governing the SSI and Medicaid programs include provisions that permit the creation of SNTs. Assets held for the benefit of a disabled individual in a properly created and administered SNT will generally not count towards the individual's Asset Limit and, therefore, do not affect the individual's ability to receive public benefits. These assets can be used throughout the beneficiary's lifetime to pay for certain expenses which will improve the quality of his or her life. For these reasons, SNTs can be an attractive option for disabled individuals who lack sufficient financial resources to pay for all of their own care needs but who have, or may in the future have (for example, in the case of an anticipated inheritance), some assets that could be used to pay for goods or services that the beneficiary cannot obtain through his or her public benefits.

In general, the following rules must be observed to ensure that assets held for the benefit of a disabled individual in a SNT will not count towards the individual's Asset Limit:

- If funded with the disabled individual's assets, the SNT must be irrevocable.
- Trust assets can be expended only for the sole benefit of the trust beneficiary.
- Trust assets must be expended only for things the beneficiary cannot obtain through his or her public benefits.
- Trust assets cannot be paid directly to the beneficiary.
- The beneficiary must qualify as "disabled" under the Social Security Act.

In most jurisdictions in the United States, SNTs will fall into one of three categories (though there may be variation from one jurisdiction to another as to the names used to identify each type of SNT):

- Self-Settled SNTs
- Third-Party SNTs
- Pooled SNTs

Self-Settled Special Needs Trusts (SNTs)

A self-settled SNT is an irrevocable trust funded with assets owned by the disabled individual who will become the beneficiary of the trust. This type of SNT may be created by the disabled individual's parent, grandparent, guardian, or a court of competent jurisdiction. The beneficiary cannot be older than age 65 at the time the trust is created.

A self-settled SNT must be managed by a trustee who is someone other than the beneficiary of the trust. It is typically important that the trustee not expend trust assets on goods or services that the beneficiary can obtain through his or her public benefits. This is because the rules governing the SSI and Medicaid programs are such that there is a substantial risk that the individual's benefits will be discontinued if the trustee uses trust funds to pay for expenses covered by the public benefit.

The trust must provide that, upon the death of the beneficiary, the state Medicaid agency will be reimbursed from any remaining trust assets up to an amount equal to the total medical assistance paid on behalf of the disabled individual. For this reason, self-settled SNTs are often referred to as "payback trusts."

Third-Party Special Needs Trusts (SNTs)

Third-party SNTs are funded with the assets of a third party (often the disabled individual's parents or other family member) for the benefit of a disabled individual. The trust must become irrevocable upon the death of the person who supplied the assets to fund the trust ("Grantor").

As with self-settled SNTs, the trustee of a third-party SNT must be someone other than the beneficiary, and the terms of the trust should direct the trustee to use the trust funds to supplement, but not replace, the public benefits received by the beneficiary. Unlike self-settled SNTs, however, third-party SNTs place no restrictions on the age of the beneficiary and there is no required Medicaid payback provision. Accordingly, when the disabled individual passes away, any funds remaining in the SNT can be paid out to beneficiaries chosen by the Grantor(s).

Pooled Special Needs Trusts (SNTs)

Self-settled and third-party SNTs are created and administered for the benefit of one specific disabled individual and are usually administered by a private trustee (often a family member of the disabled individual well-versed in the rules governing the public benefit received by the individual). Conversely, pooled trust programs allow for the assets of many disabled beneficiaries to be administered under a single umbrella program to enhance the investment potential of each individual's assets and the efficiency of administering the trusts.

Federal law requires that pooled trusts be run by nonprofit associations, and these associations usually work closely with a bank, trust company or other financial institution to undertake the daily management of the many accounts participating in the program. A separate account is maintained for each individual participant in the pooled trust program, though all accounts are pooled for investment and management purposes.

Pooled trust accounts may be created by a parent, grandparent, guardian, court or by the disabled individual him or herself. Upon the death of a disabled individual participating in the pooled trust program, the balance left in his or her account is either retained in the trust for the nonprofit association or paid back to the State Medicaid agency for Medicaid benefits paid to the decedent during his or her lifetime. Alternatively, if the pooled trust was funded with assets belonging to anyone other than the disabled individual, any balance remaining at the death of the disabled individual can be paid out to beneficiaries chosen by the Grantor(s).

All 50 states have at least one pooled trust program. Please be advised, however, that the rules governing pooled trusts vary. Further, the pooled trust programs in some states require that an attorney licensed to practice in that state be involved with the process of setting up the trust. Anyone interested in exploring a pooled trust option should contact an attorney or other qualified resource in the area in which they live for additional information.

HDSA Information

HDSA Annual Convention

Register now online for the HDSA Annual Convention in Jacksonville, FL at **www.hdsa.org/convention.**

SSA Compassionate Allowance

As of December 1, HD and Juvenile HD both qualify for SSA's Compassionate Allowance Program. HD families applying for Social Security Disability benefits will now potentially receive a decision on their claim in a matter of weeks instead of months or years. HDSA's Online Disability Toolkit can be found at **www.hdsa.org/disability** and contains information about the application process. If an individual has been denied Disability, they should contact Jane Kogan at **jkogan@hdsa.org**.

HDSA Advocacy & Education on Twitter

Follow **@JaneHDSA** to get HDSA Advocacy and Education updates on Twitter

Huntington's Disease: JOB ACCOMMODATIONS THAT WORK

Lisa Dorinzi, M.A., Consultant at Job Accommodation Network

This article is for informational purposes only. HDSA does not endorse, promote, or recommend any company or organization mentioned in the article below.

Here at the Job Accommodation Network (JAN) we provide confidential, practical guidance regarding the Americans with Disabilities Act (ADA) and related legislation. We can provide workplace accommodation solutions and technical assistance to help people understand their rights under the ADA.

JAN Consultants can help individuals with Huntington's disease (HD) learn what their rights are under the ADA and how to request workplace accommodations. We can speak to employers and explain their obligations under the ADA and suggest ways they could retain a valued employee with HD. We can provide accommodation information specific to an individual's limitations and also provide informational resources. Anyone can contact JAN to ask questions or get more information including employers, medical professionals, individuals with disabilities, and their friends or family.

JAN has provided specific tailored accommodation ideas for people with HD, their families, and their employers:

JAN HELP for EMPLOYEES

- A bill and account collector with HD contacted JAN for accommodation ideas for her concentration limitations. She requested and was allowed to relocate her cubicle, install a noise absorption panels, use a noise-canceling headset, change her work hours to quieter times of the day, and telework a couple of times a week.
- A person contacted JAN about his mother with HD who was losing her ability to speak. JAN suggested a wide array of product options, ranging from low tech communication boards to high tech speech augmentation devices.
- A medical assistant who was having trouble walking, because of her HD, contacted JAN. She worked in a hospital, so the walls were already equipped with handrails to assist her walking throughout the facility. She requested a scooter to get to further exam rooms and a mobile tablet for charting so she did not have to walk back to the main office. She also was accommodated with a modified schedule that included periodic rest breaks throughout the day.
- A person contacted JAN about her brother, a construction worker with HD, who had depression. His psychiatrist suggested and the employer granted him four weeks of leave to obtain medical treatment. The employer also provided him with a reduced schedule once he returned to work until he was able to resume his full shift.

JAN HELP for EMPLOYERS

- An employer contacted JAN about an employee with HD at a mortgage company who was not meeting production standards due to typing limitations. The employer initially provided a typing aid and later provided the employee with speech recognition software.
- An employer contacted JAN regarding a flight mechanic with HD. He was experiencing tremors that flared when he was hungry. The tremors made it hard for him to bond hardware pieces together. The employer provided a modified schedule to enable the employee to eat throughout the day and also offered weighted gloves and an arm stabilizer.

These are just a few of the successful cases JAN has helped users solve. Contact us with your HD-related accommodation issues or for general ADA information.

You can contact JAN at (800)526-7234 (Voice), (877)781-9403 (TTY), or visit the JAN Website at **AskJAN.org**

For accommodation ideas, see Job Accommodations for People with Huntington's disease at **AskJAN.org/media/eaps/employmenthdEAP.doc**

Ideas for Writing an Accommodation Request Letter at **AskJAN.org/media/accommrequestltr.html**

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Moving Together

Lundbeck

Thank you

HDSA thanks Lundbeck for the educational grant that made this newsletter possible.

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