

January 19, 2018

Dear HD Community Member:

As you may know, some members of the HD community are facing significant challenges right now in securing financial assistance to help off-set the sometimes large co-pays for chorea management prescriptions.

Caring Voice Coalition, the largest supporter of such aid, has announced that it will not be awarding any financial assistance in 2018. Visit www.caringvoice.org for more information on this decision. (Please note, we have been assured that CVC's disability assistance and health insurance counseling programs continue unaffected by this decision.) In addition, we are aware that the HealthWell Foundation's movement disorders fund has been depleted.

Prescriptions co-pays vary greatly based on health insurance provider. While these costs have always been a concern, we have been grateful for the financial assistance programs that have helped alleviate the burden and close the gap between price and access.

Since the Caring Voice announcement, HDSA has been contacting all of our partners and known HD assistance programs to identify potential resources for the nationwide HD community. It is important to note that unfortunately, due to significant infrastructure and complicated legal requirements necessary to implement a program such as this, HDSA cannot respond to this urgent need. As a result, our role is to advocate for the regulators and manufacturers alike to ensure mechanisms are in place to support HD families in accessing their prescribed medications.

Following are the phone numbers for the primary prescription resource services of which we are aware:

- Xenazine Information Center: 1-888-882-6013/ <https://www.xenazineusa.com/>
 - For patients prescribed Xenazine, which is manufactured by Lundbeck.
- Austedo Shared Solutions Hotline: 1-800-887-8100/ <https://www.sharesolutions.com/>
 - For patients prescribed Austedo, which is manufactured by Teva.
- Biotek reMedys Foundation: 1-877-246-9104/ www.biotekrx.com
 - For some patients receiving tetrabenazine (eligibility for support may be affected by insurance coverage and related variables).

Additionally, the National Organization for Rare Disorders (NORD) continues to have a co-pay assistance fund for patients being treated for chorea. We are aware that they are slow to onboard 2018 patients, but you may contact them at National Organization for Rare Disorders 1-855-864-4027 or by emailing chorea@rarediseases.org.

Most importantly we encourage you to talk with your clinician about difficulties you are facing accessing your prescription to see what options and solutions they may be able to identify.

We are hopeful that new funds will be identified in the coming weeks, and you can be sure that we will share that news with you as soon as it becomes available. In the meantime, HDSA's network of social workers is also available to help you problem solve.

Thank you for your patience as we work together through this difficult time.

Sincerely,
Louise Vetter
President & CEO