



## **Ehlers-Danlos Syndromes (EDS) Organization to Offer Community Members Health Data Management Tool**

*Backpack Health platform empowers Ehlers-Danlos syndromes & related conditions community with enhanced data access and ownership*

**Bethesda, MD and Dover, MA**– May 21, 2019 – EDS Wellness has partnered with Backpack Health, LLC to provide individuals, families, and caregivers in the broader Ehlers-Danlos syndromes (EDS) & related hypermobility disorders community with a free health data management tool. Backpack Health’s mobile platform offers an easy way to centralize and consolidate complex and detailed health data in a secure, portable, and multilingual format.

“We are thrilled to partner with Backpack Health to help those living with all hypermobility disorders and related conditions, their healthcare providers, caregivers and educators, manage, organize and securely share their health information,” said Kendra Neilsen Myles, Executive Director & Founder of EDS Wellness, Inc.

“At EDS Wellness, we focus on mind, body and spirit care for patients, caregivers and providers. Backpack Health helps us further this mission by empowering our community members to advocate for better care and enabling our members to actively pursue their lives with greater peace of mind, knowing that they have their health data with them at all times, online and offline, in any circumstance.”

In general, hypermobility related disorders, including Ehlers-Danlos syndromes (EDS), stem from the genes that impact the connective tissues. A structural or functional mutation can lead to multisystemic issues, dysfunction and disability; only to be complicated by lack of awareness, education, and compounded by misdiagnosis and preventable mistakes. Multiple family members can have the same disorder, with symptoms manifesting differently for each person. Often, these patients have large medical teams, extensive treatment plans, tremendous amounts of data, and numerous recurring appointments to track.

“EDS patients and those affected by other hypermobility related disorders face many challenges, and we strive to remove the additional challenge of care management,” said Jim Cavan, President and CEO of Backpack Health. “We partner with many rare disease communities, including multiple EDS & heritable connective tissue disorder organizations, to empower patients with complete control and access to medical information, and we are happy to extend

this to the EDS Wellness community. Our work has allowed patients and their family members to manage their health more effectively, which is especially important for the EDS & hypermobility related conditions community where multiple family members are often affected.”

In addition to offering a health management tool to the EDS Wellness community, the platform helps patients contribute to medical research by entering their de-identified data, with consent, to Backpack’s [EDS, Hypermobility Disorders & Related Conditions International Patient Health & Wellness Registry](#). With the platform’s help, patients can play an active role in research that may lead to new treatments and a better life for all those affected.

Backpack Health also provides access to a unique approach in emergency preparedness. By linking medical ID bracelets with their Backpack Health profiles, those with all hypermobility disorders, including EDS & related conditions can easily provide emergency responders with essential information about their condition, ensuring that they receive the right care in an emergency situation.

Backpack users can join by going to: <https://join.backpackhealth.com/edswellness>

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## **About EDS Wellness**

EDS Wellness, Inc. is the first EDS/HSD/Hypermobility 501(c)(3) nonprofit focused on integrative and research-based solutions, and mind-body-spirit care for individuals with hypermobility disorders, Ehlers-Danlos syndromes (EDS) & related conditions.

EDS Wellness’ mission is to provide virtual and in-person patient and continuing medical **EDUCATION**, to facilitate proper **DIAGNOSIS** for hypermobility disorders and related conditions, and to develop and implement research-based **SOLUTIONS** for patients and healthcare providers.

EDS Wellness promotes health education, integrative healthcare, and wellness solutions for restoring function & living well. EDS Wellness develops educational programs, resources and related materials on various movement, nutrition, and mind-body strategies by collaborating with healthcare practitioners and like-minded organizations, to help individuals with **ALL** hypermobility disorders, including Ehlers-Danlos syndromes (EDS), hypermobility spectrum disorders (HSD), and related conditions.

Learn more at <http://edswellness.org>.

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## **About Backpack Health**

Backpack Health, LLC builds secure, innovative information tools to help people manage their health journey – including wellness, illnesses, injuries, and chronic health conditions. The Backpack Health mission is to make it easy for everyone to access, own and control their health information to support better health care and attain better health for themselves, their loved ones and their communities. Backpack Health provides a platform for organizations to engage patients, collect up-to-date data and build communities around the globe. To assure data protection for its users' information, Backpack Health complies with the EU General Data Protection Regulation (GDPR), adheres to its data protection principles, participates in the EU-U.S. and Swiss-U.S. Privacy Shield Frameworks and does not share any user data with third parties, including social media companies. Learn more at [www.backpackhealth.com](http://www.backpackhealth.com).

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