

Inside EDS

EDS, employees garner FARA Partner of the Year honor

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Story Highlights

- EDS, an HP company, has rallied behind efforts to treat and cure Friedreich's Ataxia.
- The rare genetic neuromuscular disease generally afflicts young people.
- EDS volunteers give hundreds of hours of their own time to support the cause.

The young sufferers of Friedreich's Ataxia (FA) endure muscle weakness and loss of coordination, vision impairment, slurred speech and heart disease. These children generally show symptoms of the disease between the ages of five and 15. Currently, there is no treatment or cure for this rare genetic disease.

EDS, an HP company, and 60 employees have rallied behind the FA cause in numerous ways. In recognition of that effort, EDS was recently named Partner of the Year by the Friedreich's Ataxia Research Alliance (FARA).

Founded in 1998, FARA is an all-volunteer organization that supports education and research into treatment and a cure for FA.

EDS volunteers are giving hundreds of hours of their own time to raise money and awareness for the cause, develop technology solutions for the alliance, and serve on its board. EDSers have also provided communications support, a technology plan and consulting for a FARA quarterly newsletter. In addition, the [EDS Foundation](#) awarded FARA a grant in 2007.

EDS began supporting projects for FARA in 2003, when Bill Hartnett, a long-time EDS employee, approached colleagues Mary Beth Kosmicki, Jill Werner and Marianne Wilcox to see how the company might assist in finding a cure. EDS' executive and local leadership have been instrumental in supporting the volunteer efforts.

"I am so proud of the EDS men and women who have continually given of their personal time to deliver significant value to our cause," said John Cubbin, EDS vice president for the manufacturing business on the General Motors (GM) account in Detroit, and a FARA board member.

"They have brought the dedication and quality that EDS people are known for, as well as passion and heart," he said. "I can honestly say, the solutions developed by the EDS team have helped advance the work of the FARA-funded researchers, as we seek a cure."

Advancing the cause

FA is a rare, hereditary disease that causes progressive damage to the nervous system. It can be debilitating and life-shortening, and it often leads to full-time use of a wheelchair. Research during the past eight years is offering new promise that the disease may soon be treatable.

In a statement, FARA lauded EDS for its efforts to help the cause: "EDS employees and leadership have been active participants in the FARA community for more than five years and provided FARA with several information technology solutions that have improved FARA

programs, operations, communications and support to the scientific and patient community. In addition, these solutions have directly supported the FA scientific community in advancing clinical research in FA faster."

Darren Bielby in Flint, Mich., is the EDS support team leader and developer of the Patient Registry and Collaborative Clinical Research Network Web sites. The Patient Registry allows patients to receive communications and register as potential candidates for studies or clinical trials, while the Research Network serves clinical research centers.

"My role has been gathering requirements from FARA and distributing work to the team, in addition to implementing our applications and those from vendors," Bielby said. "Obviously, maintaining security and privacy are always at the top of our list whenever we make changes."

Bielby initially got involved in the effort two-and-a-half years ago to gain more C.Net Web experience.

"I had no idea at the time what Friedreich's Ataxia was or even how to pronounce it," he said. "But as time went on, working with the FARA personnel, RIT [Rochester Institute of Technology] students and, just recently, seeing how our efforts are matching patients to clinical trials, it makes it well worth the effort.

"As volunteers, it's definitely a challenge at times finding cycles around our normal projects, but in the end we know the effort is worth it. We have a great volunteer team here at our .NET center, which includes Brad Morse and Rod Clingaman."

Marty Ohman, an EDS consultant specialist in Rochester, N.Y., helped build an application to support the collection of Clinical Measures of FA patients that could be used as the basis for future research and studies.

Ohman and fellow EDSers Allen Chamberlain, Chris Naylor, Terry Van Fleet and Christine Ward are now involved with a Grant Management application for FARA that will be used to manage the submission, review, approval and tracking of all grants funded by FARA.

"After becoming involved in these volunteer efforts, I met [EDSer] [Margaret Ferrarone](#). Seeing her family's determined efforts in the face of this disease has inspired me to remain involved through multiple projects to assist FARA over the past five years," Ohman said.

He applauded the efforts of EDSers from around the United States who are involved in the cause.

"All of these people have selflessly given up their personal time to help all of the families affected by FA," Ohman said. "What has happened with the FARA and EDS collaboration over the past five years has made me very proud of my fellow employees, and of EDS for fostering and encouraging the volunteer spirit that drives these efforts.

"It is nice to see FARA recognizing our assistance," he added. "We sincerely hope that our efforts have helped accelerate FARA's push to find treatments and ultimately a cure for Friedreich's Ataxia."

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