

**FDA Recognizes 30 Heroes Changing Lives of Those with Rare Diseases**  
*FARA President and Co-Founder to be Honored on January 7*

**Downingtown, PA., (January 7, 2013)** – In celebration of the 30<sup>th</sup> anniversary of the enactment of the Orphan Drug Act (ODA), a law passed and designed to facilitate the development and commercialization of drugs to treat rare diseases, the FDA Office of Orphan Products Development (OOPD) has selected Ron Bartek, co-founder and president of the Friedreich's Ataxia Research Alliance (FARA), as one of 30 heroes who have made clinical, research, advocacy and regulatory contributions over those 30 years.

Selected for his remarkable work as a family advocate and founder of an organization to advance patient advocacy, research and awareness of a rare disease, Bartek will be honored alongside his colleagues during a recognition event on January 7 to be attended by those who originally assisted in the passage of the ODA, as well as former and current FDA and OOPD staff.

“I am humbled and honored to be selected as one of 30 heroes in the battle against rare diseases,” said Bartek. “Working closely with other rare disease organizations and having the support of the FDA have been vital in our collaborative effort. This recognition is something I would never have achieved without the efforts of the entire team at FARA who tirelessly work to raise awareness and research funds for a cure and of the very supportive Friedreich's ataxia families across the country and around the world.”

Since assuming the role of president after co-founding FARA in 1998, Bartek, a former 20-year federal executive branch and legislative branch United States government official, has been a champion of public-private partnership across rare diseases. One of FARA's strategies has, and will always be, partnership and collaboration.

“As a rare disease community, we cannot afford to work in isolation; we have to find common ground and share our learnings to advance treatments faster for FA and other diseases,” added Bartek.

FARA has been a champion of public-private partnership as a way to bridge some of the resource gaps and challenges in drug development for rare disease. FARA has been working with colleagues at the FDA, National Institutes of Health (NIH), private industry and other advocacy organizations to find new mechanisms and ways to work together. Several FARA-funded discovery scientists have gone on to bring new treatment candidates through the “Valley of Death” of drug development via creative partnerships and funding from multiple organizations, such as NIH and foundations. This approach has been instrumental in raising critical funds to support research, and establishing FARA as one of the top rare-disease organizations in the world.

In just 15 years, Friedreich's ataxia has gone from a poorly understood and unrecognized disease to one with a robust scientific community and treatment pipeline, including several drugs that are currently in various stages of clinical trials. In fact, a new clinical trial was launched just last

week and FARA is hopeful it will bring us one step closer to a treatment or cure for the rare, progressive and life-shortening neuromuscular disease.

“This recognition is coming at such an important time with one of our most promising trials now getting under way,” concluded Bartek. “We are certain 2013 will be FARA’s most exciting year yet.”

In addition to the recognition event, the FDA/OOPD is also planning to highlight its heroes on the FDA website and on posters that will be displayed throughout Health and Human Services agencies, and will also webcast the January 7 event internally.

### **About Ron Bartek**

Mr. Ronald Bartek is the Co-founder and President of the Friedreich's Ataxia Research Alliance (FARA); 4-year member, NIH National Advisory Neurological Disorders and Stroke Council; and former partner and president of a business and technology development, consulting, and government affairs firm. Mr. Bartek’s professional experience also includes twenty years of federal executive branch and legislative branch service in defense, foreign policy and intelligence including six years on the Policy Staff of the House Armed Services Committee; four years at the State Department's Bureau of Politico-Military Affairs, including a year as a negotiator on the U.S. Delegation to the Intermediate-Range Nuclear Forces (INF) Treaty talks in Geneva; six years as a CIA analyst of political-military aspects of the East-West balance, including a year as an Intelligence Community representative to the interagency groups charged with U.S. arms control policy; former Director, American Friends of the Czech Republic. Following graduation from the United States Military Academy at West Point, Mr. Bartek spent four years as an Army officer, serving as a company commander in Korea and an Infantry and Military Intelligence officer in Vietnam. He has a Master’s Degree in Russian Area Studies from Georgetown University.

### **About FARA**

The Friedreich’s Ataxia Research Alliance (FARA) is a 501(c)(3), non-profit, charitable organization dedicated to accelerating research leading to treatments and a cure for Friedreich’s ataxia. For more information, visit: [www.curefa.org](http://www.curefa.org)

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