



Faces of

AGENT ORANGE

Florida



Betty Mekdeci

By Jim Belshaw

If there is a moment that represents the long battle Betty Mekdeci fought to shine a light on the origins of birth defects, it might be when a court's representative wrote to her about an Agent Orange project she proposed. She was told it was far beyond her ability. It was simply too big. "Awesome," the letter said. She could not possibly do it.

"That made me so angry," she said. "You just didn't tell me that I couldn't do something. It made me really mad."

She had been engaged in the fight for birth defect information for some years. She was the co-founder and executive director of Birth Defect Research for Children, Inc. She had been in courtrooms, going up against high-powered opposing attorneys and, in some cases, even her own attorneys. She didn't do well in those court cases. Then someone told her she wouldn't do well on her own, either.

"I had been thinking a lot about birth defect research globally, why we couldn't learn anything, why typical studies didn't work, and how the major causes of birth defects had been discovered. They had all been discovered by cluster identification or what we call an Alert Practitioner, who is someone who starts seeing a number of unusual birth defects. Then they look into the background of these cases and find a common factor."

She set out to create her own Alert Practitioner, one involving thousands of people, people who were desperate to learn about birth defects.

Birth Defect Research for Children is a non-profit organization providing parents with information about birth defects and support services for children. The BDRC sponsors the National Birth Defect Registry, a research project that studies the links between birth defects and a number of causes, among them exposure to Agent Orange, an issue of particular note to Vietnam veterans.

Her interest in birth defects began in 1975, when her son was born with birth defects. Eventually, she would link those defects to a drug she had been prescribed (along with many other women) – Bendectin. Her efforts would lead to the removal of Bendectin from the world market. The initial search for information began with Betty and her mother.

In 1982, she and her husband, Mike, founded the Association of Birth Defect Children, now called Birth Defect Research for Children.

"We decided to start the organization because there was nothing for families with children who had birth defects, and it was very difficult for families to get information," she said. "I don't even remember how in the world I had the audacity to even suggest it. People are





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The Betty Mekdeci's Story Continued...

so hungry for someone to be concerned when their child has a problem.”

Since 1986, when the first Agent Orange Class Assistance Programs were funded, BDRC has worked with Vietnam veterans and their families. It was during this time that work was begun on the National Birth Defect Registry, a unique form of data collection on families with birth defects.

Working with the New Jersey Agent Orange Commission to develop the Vietnam veterans' exposure section of the registry questionnaire, the BDRC collected information from thousands of families. It found a consistent pattern of disabilities in their children.

In 1992, the association presented a report to the House Committee on Veterans Affairs and the National Academy of Science Committee on Agent Orange.

“With the Vietnam veterans' children, we found immune-endocrine problems,” she said. “We've found learning and attention problems, thyroid problems, and childhood cancers.”

She said studies of Gulf War veterans found a “structural, observable, and non-arguable birth defect, a cranial-facial birth defect.”

Today, she is working on a new approach with Vietnam veterans that will allow the veterans and families to come to a central location for extensive evaluation.

“The problem is there are so many people affected,” she said. “I've thought about this for a long time, because I've worked with veterans for so many years. What we want is centers that are funded and staffed with people who have expertise on the effects of chemicals and in this

new research. Families would be given vouchers so they have a place to stay and can be evaluated. There's a lot going on but veterans don't have access to it.”

Much more detailed information on Birth Defect Research for Children may be found on the organization's Web site – www.birthdefects.org. E-mail should be sent to: staff@birthdefects.org. The mailing address: BDRC, 800 Celebration Avenue, Suite 225, Celebration, FL 34747. Telephone: 407-566-8304.

When she began her search for birth defects information, she never imagined she would find herself with an organization the size and scope of BDRC. She never imagined that one day the federal government would be coming to her for information. She never imagined she would be in contact with thousands of people.

“It's a big dream, but when we started this, people said you can't get Bendectin off the market, but we darn well did,” she said. “They said you can't start a birth defects registry, but we darn well did.”

Significant numbers of Vietnam veterans have children and grandchildren with birth defects related to exposure to Agent Orange. To alert legislators and the media to this ongoing legacy of the war, we are seeking real stories about real people. If you wish to share your family's health struggles that you believe are due to Agent Orange/dioxin, send an email to mporter@vva.org or call 301-585-4000, Ext. 146.

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