



## *Disability Awareness Newsletter*

*Knowledge, the Key to Understanding*

U.S. Department of Agriculture, Research, Education, & Economics, Summer 1997

DAN encourages REE employees who have or are familiar with a disabling condition to share in future issues. Comments on content or suggestions for future issues may be forwarded to Sue Dixon, Recruitment, Examining, & Demonstration Staff, Room 113, 6305 Ivy Lane, Greenbelt, Maryland 20770. Phone: 301-344-0134; FAX: 301-344-2962; E-Mail: [sdixon@ars.usda.gov](mailto:sdixon@ars.usda.gov)

### REFLECTIONS ON LIVING WITH DYSTONIA

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Dystonia attacked me in 1966 when I was a sophomore in college. Dystonia is rare; only one in 10,000 has developed the type I had then. Although I have lived with Dystonia continuously since then, it was not until 1991 that my doctors really diagnosed me with Dystonia. I had a form of Dystonia called spasmodic torticollis (or just ST for short) diagnosed in 1967 after visits to many specialists and even the Mayo clinic in Minnesota. ST caused my neck muscles to twist my head to one side. In fact ST is so rare, the first person I ever met with ST (outside doctors' offices) was in the spring of 1996. Although ST caused many problems, my life was quite normal. I kept going to college, participated in the corps of cadets at Texas A&M University, completed my degree on time, and remained active in the sports that I loved - golf and basketball. I got married my senior year in college. With much help from my wife, I made it through graduate school completing my M.S. and Ph.D. degrees. From 1968 until 1991, my Dystonia problems were relatively minor. In the late 1980's, my voice began to get weaker, and it sounded hoarse or strained (this is called spasmodic dysphonia - SD). In 1991 other Dystonia problems became more evident (tremors in my head and hands). I was never in constant pain like many with ST, but SD really began to change my life and even forced me to make some workplace accommodations.

ARS offered me a job in 1979. I do not think anyone even cared that I had ST (or even knew it, despite the obvious strange posture of

my neck). I never made a "big deal" out of ST, but with SD it became more difficult to "disguise" my condition. I doubt many at my laboratory even know that my condition is named or much about it. Of course my colleagues throughout the U.S. that have known me for some time probably have recognized the changes that have occurred in recent years, particularly as my voice changed. I was asked to serve as research leader (RL) of the Water Management Research Laboratory in 1994 and still serve in that capacity.

What problems has Dystonia caused in my life and in my job? Well, ST has not been a major limitation, although for many others it is a great disability often resulting in loss of job function. Dystonia has affected the hand and arm muscles that influence my handwriting. In college, my handwriting got noticeable poorer, and now it is barely legible even to me! Fortunately, I can use computers for most of my day to day needs. SD has been the biggest hurdle with which to deal. Simple tasks like staff meetings, telephone calls, and giving speeches are now major jobs. I use e-mail and fax communication more often now rather than attempting to send handwritten notes or even calling someone on the telephone. Of course, communicating well orally is necessary for an RL. So I use handouts and spend more time making my visual aids (slides or overheads) as effectively as possible. SD does make it difficult to speak clearly and distinctly at times.

\*\*\* What is Dystonia \*\*\*

Dystonia is not a new disease. It has no known cause and no definitive test for diagnosis. It affects nerve signals from the brain to various muscles. Some Dystonias are inherited, some result from drug induced effects, and some result from brain injuries. It is also known as a movement disorder and is usually diagnosed by trained neurologists or specialists in movement disorders.

Generalized Dystonia affects a wide range of body areas and usually occurs in childhood, often affecting the limbs and feet.

Focal Dystonias affect specific body parts, but sometimes patients may suffer from more than one type of focal Dystonia. These typically attack at mid life (40s to 50s). Common focal Dystonia affects the following:

- muscles in the neck, head, and spine.
- involuntary contraction of the eyelids
- the jaw, lips, or tongue
- muscles that control the vocal cords
- fine hand functions

\*\*\* Treatment \*\*\*

Dystonia is treated by a variety of medications designed to reduce muscle spasms. In a few cases, specific surgery may be needed, but often surgery is not a viable option. Recently several forms of focal Dystonias have been treated with Botulinum Toxin Type A (BOTOX). Botox is injected in extremely small amounts directly into affected muscles to "weaken" the muscle or to actually "block" nerve signals telling the muscle to contract.

\*\*\* DIAGNOSIS \*\*\*

Diagnosis is difficult. A survey from the National Spasmodic Dysphonia Association (NSDA) reported the following facts:

- patients had to consult an average of four doctors over an average of five years before receiving a diagnosis
- 71% of those surveyed had difficulty in obtaining a correct diagnosis (70%

reported that physicians whom they consulted were unaware of the disorder)

- 75% reported they consulted general practitioners and only 4% of the respondents reported being correctly diagnosed by general practitioners
- 71% reported reduced social life; 31% reported reduction in work hours; and 26% reported they could not work.

\*\*\* Celebrities with Dystonia\*\*\*

A few well-known people with Dystonia include Chip Hanauer who has SD and pilots the hydroplane, *Miss Budweiser*. He is the record winner of 10 Gold Cups and serves as a national spokesperson for SD. Senior PGA golfer Doug Sanders has recently begun playing competitive golf again after developing ST. Several professional musicians, like pianist Leon Fleisher, have developed occupational Dystonia (or writers' cramp) that cut short their careers.

\*\*\* Where to Find Help \*\*\*

Dystonia Medical Research Foundation  
One East Wacker Drive, Suite 2430  
Chicago, IL 60601-2001  
(312) 755-0198 or (800) 377-DYST  
E-Mail: [dystfndt@aol.com](mailto:dystfndt@aol.com)  
Internet:  
<http://www.ziplink.net/users/dystonia>

National Spasmodic Dysphonia Assoc.  
P.O. Box 203  
Atwood, CA 92811-0203  
(714) 9621-0945 or (800) 795-6732

National Spasmodic Torticollis  
Assoc.  
P.O. Box 424  
Mukwonago, WI 53149-0424  
(800) 387-8385  
Internet:  
<http://www.bluheronweb.com/nsta/nsta.htm>

**THE NEXT ISSUE OF 'DAN' WILL  
FOCUS ON SLEEP DISORDERS**