

## **THOUGHTS ON ALS AND THE LES TURNER FOUNDATION**

By TIM SPANN 4/26/09

Like many families, we did not think much about how we might die, just about everyone in the family died of heart disease in their seventies. Although we had empathy toward those struck down by chronic disease, we were almost certain that would not be our fate. We believed all we needed to do was work hard and then someday after we retire, things would end quickly.

Last September at age 49, my assumptions about living and dying were shattered when I was diagnosed with bulbar form of ALS. Nearly instantaneously, the plan of working 15-20 years was displaced with the vision of a disability, which was already relentlessly grinding up my body, destroying muscle and nerve until various functions are gone. Eight months ago my voice was horse and weak. Now my voice is almost gone and few can understand me. Eating and drinking have morphed from a pleasurable social activity to an awkward chore requiring concentration to avoid accidental choking. Now my hands are getting weak, I have a hard time buttoning a shirt and am beginning to drop things. With weak hands and a bad voice I am unable to communicate fast enough to efficiently practice law and am currently disabled.

I know that unless a cure is found soon, it will not be long until I lose more motor function and will have trouble caring for myself. This process will almost certainly continue until I will be unable to voluntarily move my body and eventually unable to breathe and at that time will die or be dependent upon a respirator. I am not sure any person or family is prepared to face this diagnosis. However, one saving grace of being diagnosed with ALS is the overwhelming support that our extended family and friends have showered upon us. Nevertheless, a diagnosis of ALS is a challenge that sorely tries the emotional and financial resources of any family.

The Les Turner Foundation and its staff at Northwestern Hospital have provided my family and the families of ALS patients throughout the Midwest with essential support that prevents us from being overwhelmed by this dreadful ailment. The wonderful and caring doctors, nurses, technicians, social workers, and allied healthcare providers form an integrated support team. This team knows the problems ALS patients and their families face. More importantly, the staff of the Les Turner Foundation knows techniques that can solve or lessen many of the problems that ALS patients face. Whether the problem is loss of weight, communication difficulties, depression, transportation needs, home hazards, mobility issues, or countless other problems, the Les Turner Foundation has possible solutions. Their integrated approach means that we do not have to spend days or weeks seeking out the right professional to provide assistance. Instead when we go to the Northwestern clinic for a check up, we simply request to also see the appropriate caregiver. The Foundation's staff has also come to our home to suggest modifications to our home to ease future mobility issues and to provide emotional support and to suggest other resources to help our family meet the challenges of ALS.

Both the initial diagnosis of ALS and living with this relentlessly progressive disease often feels like being battered by a turbulent sea. For our family, the Les Turner Foundation and their wonderful staff are a welcomed rock of stability that helps us brace against the awful angry sea of ALS.