SONG IN THE NIGHT

## The Impact of Disability on America's Families

- \* Few people realize the catastrophic effect that caring for a disabled family member has on an entire family. Caregiving is a 24/7 job with little or no respite, especially if the disabled person has high medical or emotional needs.
- \* The internal pressure a family feels is tremendous. Often the needs of the individuals are sacrificed as the overwhelming needs of the disabled member takes precedence. The others can also suffer from "survivor's guilt" as they watch their loved one suffer.
- \* Besides the physical and emotional cost, there is often a high financial burden in caring for a loved one. Someone has to lay aside a job or career outside the home, incurring a substantial loss of income. In addition, it is estimated that the associated costs in a family caregiving home is about 2.5% greater than for a normal American household.
- \* Families caring for or otherwise impacted by a disabled family member need long-term loving support from the community and the family of faith. These families are running a marathon of sorts, and while it is easy to give in to "compassion fatigue," those around them can know that even a simple gesture of caring is priceless to a family who often feels isolation and despair.

## Simple Ideas for Squashing "Compassion Fatigue"

- \* Narrow your focus instead trying to help everyone. Choose and get to know about one person or family.
- \* Make your goals simple. Just an e-mail to say hello can make someone's day.
- \* Don't let guilt keep you from making a contact. If you've let a friendship slide, just pick it up again. They'll understand.
- \* Be patient. Keep your own expectations low. A caregiving family operates differently than the rest of us.

## When is a Medical Treatment Futile and Who Gets to Make That Decision?

- \* How sophisticated medical technology has blurred the boundaries of life and death.
- \* Recent court rulings, strained budgets, and strange medical mysteries have re-ignited the ongoing battles of who gets those coveted hospital services and who must die.
- \* How those with disabilities feel about the current national climate on the right-to-life versus "death-with-dignity" debate.
- \* The urgent need for organs speeds the time of determining "death" for some patients.