

## **Testimony**

### **Ken Jackson**

Three of our four family members – my wife and our two sons – have ME/CFS. It would be impossible to relate all the ways this illness affects our family in such a short time, but here are some of the challenges we face every day:

- Recurring cycles of illness/health, school attendance/makeup work, participation in/cancellation of planned activities and couch time, plus the parental worry and relief that accompanies these episodes.
- The agony of having to make decisions about letting your child participate in "normal" activities knowing that it might result in a severe crash and missed school.
- When school is missed, there is the stress of making up schoolwork with greatly reduced energy and available time compared to a healthy child.
- The difficulties of beginning each new school year, having to build understanding of my sons' illness with teachers and administrators and then struggling to gain their true cooperation when my boys are crashed for days (or weeks) at a time and the reality of what needs to happen sets in.
- The relief of the beginning of summer vacation when my sons can self-regulate their activity, rest when they need to, and have free time to de-stress their lives and feel more normal.
- Because my wife is also ill, I bear the stress and responsibility of retaining a good paying job with good benefits in bad economic times, not allowing myself to get sick, coming home from a full-time job to take care of whatever housework my wife couldn't do, and balancing necessary work travel with support and care of a family with chronic illness.
- Our health care costs continue to rise each and every year and we wonder how we will be able to handle the skyrocketing cost of upcoming college expenses.

All of this is accompanied by the nearly constant anxiety of what the future holds for my boys. How will they be able to handle college, find employment, and live on their own? Will they get better or worse? Will they continue to struggle or finally find effective treatment and a way out of this illness that has taken so much of their childhood?

We ask the committee's help in pushing for more research in the area of pediatric

CFS, for the sake of my kids and all the other families in the US who are struggling with the same issues.

Ken Jackson