

## Summary – Advice from a Disability Advocate

### Valerie Powers Smith

Wendy Helmka understands how important advance directives are for an adult patient with mitochondrial disease.

"The doctors told me that I would have died if I had not had the advance directive, or if I had not been able to go home with 24-hour nursing care. I would have been put in a nursing home where medicines used to treat my symptoms would have damaged my mitochondria even more, and may have killed me."

Wendy recognizes that adult patients and parents of children with Mito need to be very proactive in planning for the uncertain and unexpected aspects of the disease. "You need someone to speak for you when you cannot speak for yourself," she says.

Guest speaker and attorney Valerie Powers Smith took patients and parents on a crash course in the area of disability law. "If I could emphasize one thing to all people with mitochondrial disease, it would be the importance of proactive planning, and understanding the basics about everything from your estate plan to your insurance benefits."

Valerie spoke about the importance of appropriate planning for assets, special need trusts, and estate planning - for both children and adults who are disabled. MitoAction listeners were surprised to learn that children with assets (including inheritance, savings accounts, bonds and trust funds) greater than \$2000 in their name would negate some state and Federal benefits, including supplemental insurance (Medicaid). Planning for a child as he/she approaches the age of 18 is important so that the child does not have more than the allowed amount of resources for at least 5 years prior to the child's 18<sup>th</sup> birthday (i.e. the age of 13). Similarly, the income threshold for people over the age of 18 is \$800 per month in order to qualify for supplemental income (SSI). By law, at the age of 18 a person, despite their disability, is considered an adult who must manage his or her own care. Considering and identifying power of attorney and legal decision-making guardianship are important considerations during a minor's teen years, as well as special needs trusts in order to protect the child's future eligibility for coverage. When advocating for a person with a disability, Mrs. Powers-Smith is sympathetic to the demand on the patient or caregiver and the confusion that many people face when trying to access available state or federal services or insurance coverage. Medicaid, social security income, and eligibility requirements can be accessed at <http://www.cms.gov/>. Early intervention services are a prime example of an under-recognized area for supplemental support for all children with developmental delays under the age of three. After the age of three, an IEP (individualized education plan) is developed and includes school placement recommendations.

Medical necessity and denial of services by insurance are frequent challenges for many Mito patients, especially in areas where the disease is not commonly recognized or

treated by community physicians. Valerie's first line of defense is to know the details of the plan and benefit package, and to always keep an updated a copy in writing.

"Understand the type of plan that you have. Just because a service was denied does not mean that it is not covered," she comments. Typically, an appeal or re-processing for insurance, Medicare, or Medicaid should occur within 12 months from the date of service. Often there are three levels of appeal, and probably includes an external level of appeal by either the State Department of Insurance or by the Federal government. Employer self-funded or self-insured insurance plans are the most difficult for many people with disabilities, as this type of plan has coverage limits chosen directly by the employer. Individuals can request an appeal response within 72 hours for urgent circumstances. Medicaid recipients can file an appeal within 10 days of a denial or termination of services which then mandates keeping the same level of services until the final decision on the appeal.