

## **Summary – Special Needs Planning Jack Raycroft**

### **How to plan for the future can be baffling: how can anyone plan for the future when day-to-day details are overwhelming?**

Though there are certainly many specific obstacles, especially for an unpredictable and individualized disease like Mitochondrial disease, there are some "best practices" that can be followed to begin the planning process. Just thinking about a plan, even taking a very small step, can bring peace of mind and the ability to take the next step or steps in the planning process. As Jack Raycroft aptly puts it: "How do you eat an elephant? One bite at a time!"

### **Best Practices**

- Become educated about what is available in the way of financial plans.
- Take some action - no matter how little - it will help.

### **Basics**

(These will all depend on the kind of family constellation you have; i.e., single adult/married adult no children, family with one affected child, family with multiple affected members.)

- Seek benefits.
- Protect eligibility for the future. (Make sure all systems - financial, legal & social - are in place and will continue when you are not around.)

### **Smart Planning**

- Begin with a "Letter of Intent." This is a very specific letter you write in which you tell those you leave behind exactly what you want for your loved one. You cannot trust that others will know all the little things that you know and that are important for your loved one. It could contain their life's hopes and dreams or it could include a list of those doctors and nurses you love and those you don't ever want your loved one to see! This letter can be quite long and should be updated periodically. Though it is not a legal document, it can be used to help sort out issues; for example, this letter of intent can be a guide when selecting a guardian for your loved one. Jack Raycroft has a template for a letter of intent and can be contacted for a copy.
- Apply for SSDI. This is disability insurance and if someone is disabled, they should apply for this. Almost always people are turned down the first time they apply; they should, however, reapply until they are satisfied. If needed, special legal counsel may be used (Disability Attorneys are expert in this area).
- Create a Will. Use this document to appoint a guardian.
- Write a Living Will. This document will declare your final wishes if, for example, you are in a coma and cannot tell others what your wishes are for medical care, etc.
- Name Durable Power of Attorney. This is needed if your signature or agreement is needed for a transaction (spouse cannot sell or buy or do something without your signature). This document allows the action to go forward because you have given someone else the power to act for you should you be unable to sign/agree due to incapacitation.

- **Protect Eligibility.** Government benefits (SSI, Medicaid, etc) look at income level as well as assets. The limits are very strict (not greater than \$2000 in assets and not greater than \$1000/month income for Massachusetts). So, keep assets and income below that amount if this is what you will be relying on for help. Some people prefer to allow the child/adult develop as full a life as possible and forgo this assistance so that they can pursue a career or maintain a job...it is a very personal decision.
- **Fund the Future.** Be sure to consider the financial needs of both the dependent as well as the care giver. Make sure that assets will be transferred at your passing according to your wishes. This can be very different for each of us. As we have seen recently, real estate and investments can be unpredictable, so Life Insurance has been a good way to supplement future financial needs. Another important consideration is where that money from the Life Insurance policy goes; it should go into a trust for the special needs person - not to the individual dependent. Why? Because this allows the dependent to keep their assets at the minimum level to receive government help. For example, a trust can be set up in your child's name with the trust as the beneficiary of your life insurance policy. "Morally obligated giving" is not a good idea. By this we mean leaving siblings in charge of caring for their special needs brother or sister.
- **Coordinate planning with other family members.** This means letting everyone in family know what the financial plans are (grandparents, godparents, etc) . They can donate or help with a trust, rather than give money directly to child. You do not want to make the child ineligible for benefits because a wonderful family member left them some money directly.
- **Integrate financial, legal & social planning.** This means developing social networks and teams. Ask others if they will continue their activities with your dependent after you are gone. "Can Sean still go fishing every summer with you? Can Meagan still spend her school vacation with your children?" There are organizations that can help you with this.
- **Work only with special needs professionals.** There are lots of folks who have good intentions and will want to help, but if they don't work with special needs planning all the time, they do not have the expertise necessary. Met Life has special Divisions all over the country even though this presentation today has focused on the laws in New England. Jack Raycroft will be happy to talk with anyone and refer them to an appropriate professional in their state or country. Jack is available for a complimentary consultation to discuss your specific situation. In the greater Boston area, he can be contacted at 781-876-4125.

### **Final thoughts:**

Because Mitochondrial Disease is unpredictable and takes so many different forms in different people, it is difficult to give exact advice to everyone. It does seem as though long term health insurance would be difficult if not impossible to obtain, so adults certainly must consider long term savings as part of their plans for the future for themselves and/or their loved ones . Setting up trusts may be another way to help meet future financial needs. Because persons with Mitochondrial disease often do not appear ill or disabled, it may take extra assistance to plan adequately for your future. Use a Disability Attorney if needed. Doctor's do not generally want to get involved with

petitioning the government for disability applications. They will generally provide you with needed records, but that is all. This may become complicated because of the often-fragmented care Mitochondrial patients receive due to the length of time it takes for the disease to be diagnosed and because of its various manifestations. For this reason, if a general letter describing Mitochondrial disease is needed, contact Cristy Balcells (director@mitoaction.org), Executive Director of MitoAction; she will be happy to try to assist you.

It is not too soon to start planning now. Peace of mind will follow once you begin your plan.