

You can make a difference.....

By Rosemary B. Randazzo

I am a parent of 3 children with Cystic Fibrosis (“CF”). If you are not familiar with CF, it’s a very costly and time consuming disease. There are many medications and treatments which take a lot of time and money. Years ago we were told, **by another parent**, about this wonderful program called the Physically Handicapped Children’s Program. It is a financial entitlement program funded in NYS under the Maternal Child Health Block Grant. Eligibility is based on salary and resources. I wasn’t working at the time and we were approved. It was wonderful. This program would pay all co-pays for medications, doctors, labs, etc. related to CF only. Time went by and I got a little part time job and my husband would work overtime so we could afford clothes and food! As this program has a yearly renewal we were then “kicked off” the program.

I wrote many letters and contacted many people because I truly could not understand why eligibility calculations were not based on the number of children in a family that are afflicted with a diagnosis and not just the number of people in our family. I also kept mentioning the number of spend downs that my family incurred with said diagnosis.

Lo and behold. the Physically Handicapped Children’s Program did, in fact, change their eligibility criteria to reflect families with *more than one* child affected by a diagnosis. If you are applying for a program and have more than one child with any particular diagnosis look into the eligibility criteria. Do not be afraid to write letters and voice your concerns. ***Things will not change unless you do something to make it happen!***

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