

**Testimony of Rabbi Samuels to the Appropriations Committee  
Regarding the Department of Social Services budget for Fiscal Years 2010-2011  
February 11, 2010**

Senator Harp, Representative Geragosian, members of the Appropriations Committee, thank you for the opportunity to speak with you today. My name is Rabbi Samuels and I am here to speak to you about the impact that the state budget could have on Connecticut Children's Medical Center and the critical resources that it provides to my community and my family.

12 years ago my wife Blumie, our 3 kids and I moved to Simsbury CT to open a Chabad Education Center. At Chabad of the Valley we provide multiple services to the community such as classes for children and adults as well as marriage and teen counseling. Little did we suspect, 12 years and 3 additional children we would soon be the ones on the receiving end and in need of invaluable services for our own family.

On January 29<sup>th</sup> 2009 God blessed us with a sixth son. At first everything seems to be ok but before long it was evident that something was amiss. Raphael had very weak sucking ability and appeared to be what is called "floppy". The doctors and nurses in the NICU at CCMC were extraordinary. Each one was more friendly, warm and knowledgeable than the next. Out of the many exemplary services provided by CCMC one in particular cut straight to our hearts in a profound way. The "coddlers" were volunteers that came to the NICU solely to hold my son throughout the night so he should constantly feel that warm human touch. This experience we've come to learn, was just one of the many ways that CCMC truly goes that extra mile to make a significant difference in the lives of countless families in need.

Of the many tests Raphael needed, Suzann from the feeding team at CCMC suggested our son be tested for a very rare disorder called FD or Familial Dysautonomia. She had recently returned from a conference where someone had mentioned something about FD. Needless to say the test was going to take 2 and 1/2 weeks and though we did not expect anything we had to rule it out. After spending a month in the NICU the doctors at CCMC felt that they had done everything they could and suggested we move our son to Boston Medical Center for further testing.

It was a Friday morning when we quickly transferred Raphael to the huge grounds of BCH. We spent a long weekend there and Monday morning we received the heartbreaking news that the unthinkable had happened. Our son Raphael had tested positive for FD. I remember seeing our lives flashing before my eyes and feeling overwhelmed by utter despair and helplessness.

**What is familial Dysautonomia?**

Familial Dysautonomia or Reilly-day syndrome as it is also called, is a rare (only about 300 people in the world are known to have it) recessive disorder that affects the autonomic system, our autonomic system controls everyday things that we may take for granted, such as, breathing, swallowing, body temperature, blood pressure, tears, pain sensation, heart rate and much more.

The doctors in Boston informed us that there was only one doctor in the world who specialized in FD. We needed to immediately transfer our son to NYU to see this doctor. Our time in NYU made us long for the NICU at CCMC. We couldn't wait to get out of there and return to CT. For the next 4 months we had to frequent CCMC every time we had what is called an "autonomic crisis". The care in the ED was exceptional, and once again on many occasions saved our sons life.

On December 11<sup>th</sup> 2009 we noticed something was very wrong with Raphael and we rushed him to the hospital. Our unbelievable surgeon Dr. Fink who was just finished her shift and on her way home, looked at the X-ray and determined that our son needed immediate surgery, but instead of giving it over to the next doctor on call she remained all night, performed emergency surgery that saved our son's life! Not surprisingly the care in the PICU was phenomenal the attentiveness from everyone we came in contact with, exceptional. At one point a musician offered to come into our room to play the harp. It was one of the most beautiful and peaceful melodies I have ever heard and really helped to calm our otherwise frayed nerves.

**One thing that really impressed me was the equal care that is provided to everyone that walks through the doors at CCMC regardless of their ability to pay, insurance or lack thereof.** A baby that was in the room next to us was there for 8 months and the doctors and nurses took care of him as if he was their own. One example of the dedication of the staff was readily apparent one day when I noticed two nurses pricking each other with a needle. When I inquired about this strange behavior they explained that they were testing to see how the patient feels and trying to determine the best way for them to administer the test that would cause the least amount of pain. Every single child is unique to them and is treated with the same unparalleled care and attention.

Very little is known about this disorder only a few doctors in the world know about this disorder two of whom are in NY. More than one family with an FD child has moved to NY to be close to these doctors. At first our family thought we might have to follow the same route, but a little time spent at CCMC changed all that. My wife and I found that CCMC was the place for us. One example of that was that before any nurse or doctor walked into our room they made sure to read up on FD so that they could discuss our options in a knowledgeable way. Such dedication is rare, but at CCMC it's the norm. After being at some of the biggest hospitals in the country NY and Boston, I can confidently say that CCMC is second to none. And today I am happy to say that a family living in Buffalo NY, whose child unfortunately also has FD is thinking of moving to Hartford just to be next to CCMC.

I cannot think of a better or more worthy institution to receive government funding than one that regularly saves the lives of so many children. I cannot fathom any child in need being turned away. I implore you for the sake of my son Raphael and all the countless other children to make sure to continue and add to the crucial funding of CCMC.

Inadequate payments from state sponsored health care programs will jeopardize Connecticut Children's Medical Center's ability to provide all the care that children and families deserve. I ask the Appropriations Committee to preserve Connecticut Children's critical resources when making decisions this year about the state budget.