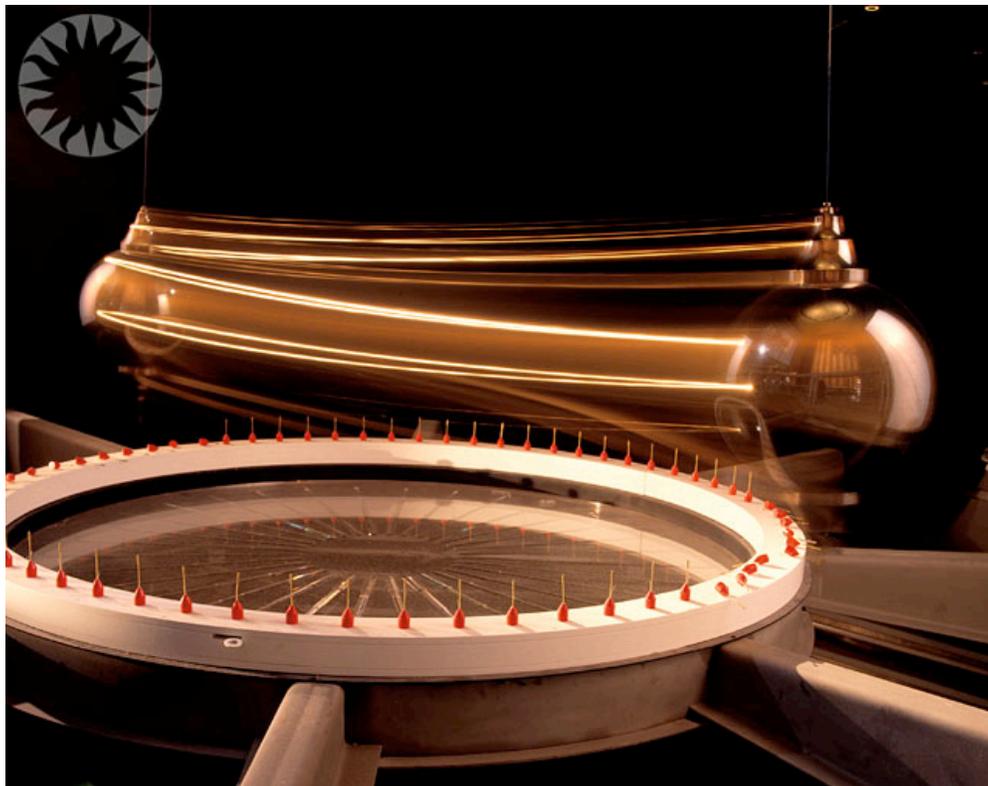


# Complex Child E-Magazine

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## Swinging the Illness Pendulum by Erin

As a child, I was fascinated by the swinging Foucault Pendulum at the Smithsonian's National Museum of American History in Washington, DC. Its movement mesmerized me, watching it swing back and forth in a predictable rhythmic and hypnotic fashion, knocking over a ring of pins as it completes its trajectory around the dial. Although the Foucault Pendulum is set up so that it makes a predetermined journey around the perimeter of the dial over 24 hours, I have found, nevertheless, that the movement of a free-swinging pendulum has powerful meaning while parenting a child with a chronic illness.



So much of my daughter's chronic illness is out of my control, beginning with its origin and ending with very concerning outcomes, such as her uncontrollable seizures. Each outcome maps out as a finite destination along our journey, and I imagine the trajectory of our journey being similar to that of a free-swinging pendulum, traveling in large and small arcs until its movement ceases. That is, our journey does not follow a straight line

but instead, like a pendulum, has a trajectory that is not fixed but subject to the influence of multiple factors.

The goal is stabilization of my daughter's illness for optimal functioning. Therefore, smaller arcs in the trajectory of the illness pendulum are preferred, because they represent manageable aspects of the illness, and allow a quicker return to her baseline of zero movement. Larger arcs are less preferred, because those represent serious health issues that can dramatically change her functioning and our family's well-being, and require more invasive medical interventions for stabilization.



Another Foucault Pendulum from the Ciudad de las Artes y de las Ciencias de Valencia by Daniel Sancho

Our journey includes periods of motion and stillness, typically with factors out of my control (e.g. cold season) kick-starting the movement of the illness pendulum that represents changes in her health.

At times when factors out of my control suddenly cause new issues to threaten my daughter's health, I swing with the illness pendulum into crisis mode, taking care of the most pressing health issues to help stabilize her functioning. Collaborating with her doctors, I try to have an impact on the movement, hoping that my caregiving efforts will slow down the acceleration, create shorter arcs, or throw the path an inch or two off center, thereby changing the trajectory to ultimately avoid larger setbacks in her functioning.

After the crisis is managed, I let the illness pendulum swing its way back to zero motion,

making only minor adjustments to its course or its speed to encourage optimal baseline functioning. When it appears that another threatening health issue may be resurfacing, I will once again swing with the illness pendulum into prevention mode, taking steps to best ensure that the crisis does not occur again.

At times, similar to traveling on any journey in life, I am hypnotized into complacency by the smaller, more manageable arcs of the illness pendulum. If an uncontrollable factor later kicks the illness pendulum into a larger arc, it feels unexpected and brings up strong emotions. These blind me to the fact that we have dealt with similar powerful arcs before and managed to return her to a stable state of functioning, albeit sometimes a new baseline functioning.

At other times, the complexity of my daughter's illness makes it seem as though the pendulum is in constant motion, because the minute one aspect of her functioning is stabilized, another suddenly gets kicked into motion again. During these times I can feel as though I am waiting for the next pin to get knocked over by the larger arc of the illness pendulum, instead of actively trying to prevent more serious health issues from occurring. With so much happening at once, it is easy to focus on the fact that we are constantly moving in circles, seemingly unable to return to any baseline.

During more challenging moments, however, a simple sign from my daughter, such as a smile, reminds me that she has the determination to use whatever functioning she has to counteract the movement of her illness pendulum. Therefore, following her lead, I must also swing into gear once again.

Each time our collaboration with her doctors has made even just a small impact on the trajectory of her illness, I gain more strength to put aside my fears and try to influence the next arc of the illness pendulum in order to maintain her quality of life. That is, each small success reminds me that together we create our own powerful swinging motion, and are definitely a force to be reckoned with.

*Erin has a PhD in Clinical Child Psychology but is currently focused on taking care of her three children's needs. Her second child, Brooke, has multiple severe disabilities as a result of unexpected complications around the time of her birth. She is 100% dependent (non-verbal and non-mobile), requiring tube-feedings, catheterization every few hours, supplemental oxygen and hydration overnight, vagus nerve stimulation, special positioning and creative caregiving. She has been diagnosed with severe cystic encephalomalacia, chronic kidney failure, secondary microcephaly, reflux, cortical visual impairment, severe cerebral palsy, sleep apnea, refractory epilepsy and a neurogenic bladder. Erin documents how her family keeps Brooke happy and engaged on Adapted World [<http://adaptedworld.wordpress.com/>].*