RUN FOR ISIS

Dear Friend:

Your contribution to the **Run for Isis** these last two years has made a tremendous impact on my niece, Isis. I want to express thanks and gratitude on her behalf. Once again I have chosen to do the **Run for Isis**, more specifically, the <u>Columbus Marathon</u>, for the third year in a row, and I am asking for you to consider a financial contribution to enhance her life. In just two years we have all raised \$25,000!

Isis has spastic, athetoid quadriplegia Cerebral Palsy and, barring phenomenal breakthroughs in medicine, she will remain speechless and confined to a wheelchair for the rest of her life. I raise money and put my body to the test each year so that Isis can attend a private physical therapy clinic, Euro-peds, where they afford her every conceivable possibility for inclusion in everyday life.

To date your contributions have made a considerable difference. Since 2005, the first year of fundraising, Isis has made three trips to <u>Euro-peds</u> (each trip costs approximately \$6,000) in Pontiac, Michigan where she has benefited from 120 hours of one on one physical therapy. That's more PT than most children with cerebral palsy receive in 2 ½ years. This intensive therapy has helped Isis learn the basic proprioceptive knowledge that in order to walk she must lift one leg at a time - something she had no concept of before April of 2006, which was her first of three trips she has made to Euro-peds.

Nothing could have prepared me for the first time I met Isis, especially since I was a new father of a typical, able-bodied child. I had learned enough about cerebral palsy through another source of inspiration, Dick and Rick Hoyt, but this was my niece! Given the complexity of her birth, and the length of time her brain was without sufficient oxygen, doctors did not expect Isis to live through her first night. But she did. And she lived through the infantile spasms, which caused her to need intra-muscular injections of steroids 2 times each day for 3 months. She lived through the placement of a feeding tube directly into her small intestine, which gave her all of her nutrition for 6 months. Isis now eats by mouth, and can swallow thickened liquids, although she still has a tube in her stomach so she can get fluids and the three medications she takes daily.

Isis has a wonderful spirit and tremendous will to live. She has an irresistible smile. Her disposition is sunny; she laughs at goofy jokes, adores music and watching people dance, and generally movement of any kind. How unfortunate that she was born into a body that has made purposeful movement of any kind a mist, a wisp of a scent that constantly eludes her.

Through years of physical therapy, Isis took her first steps at age 4. But she doesn't walk the way typical kids do. She cannot run full force across the room and tackle me to the floor like my son does. She can be strapped into a gait trainer and, if someone pushes, she can take steps from the gym in her school all the way to her classroom. Just this week she rolled over independently. She is 5 years old. She has never fed herself, ran though a field, or told her mother she loves her...with words...she speaks volumes with her eyes. Get to know Isis, and you will notice a little girl who is very rowdy, and would like nothing better than to have dirt under her fingernails and a black eye from falling off of something she knew better than to climb. She is a normal girl

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trapped in a body that will not allow for movement and a mind that as of this point cannot offer self-expression.

Like all children, Isis is growing every day, and growth spurts that cause typical children some aches or pains can be devastating to a child with cerebral palsy. A large growth spurt could cause Isis to lose the somatic knowledge she has learned over the long and grueling schedule of therapies. Growth spurts can cause muscular weakness and risk of spinal curvatures, or scoliosis, which can only be corrected with bulky braces or neurosurgery to straighten the spine. Currently Isis has a sixteen-degree curve in her spine, so these are possibilities we fear and prepare for.

The only hope for this rather dire setback is the possibility housed in the little body and enormous mind of Isis. Intensive therapy at Euro-peds helps tone and exercise her body, but it has also gives her a chance to be in a place where she belongs and where people really believe she has the potential to excel. This is why I run a marathon on her behalf: I believe in and honor her quest for independence and inclusion in community activities, sports, school and, eventually, perhaps employment. I train hard and run as fast as possible to glorify the independence you and I take for granted.

Suffice it to say, your contributions these past two years have helped Isis avail herself of opportunities, which previously were out of her reach and made them possible. As with training for any race of any distance, preparing Isis for a better life starts with one day at a time. Can you help me get her closer to her life dreams by contributing again this year? Your consideration is deeply appreciated.

You may contribute in two ways:

• Your contribution can be tax deductible. Make your check payable to the North Oakland Foundation. This is an IRS compliant 501(c) 3 non-profit organization affiliated with Europeds. Please put **Isis Lynch** in the memo section of your check. These contributions are deposited into an account for Isis's therapy at Euro-peds.