



Our daughter Madison was recently diagnosed with a neuro-degenerative disorder, for which there is no cure. It is called BPAN, an NBIA (Neuro-degeneration with Brain Iron Accumulation) disorder.

There are fewer than 100 cases in the world. Being that it is so rare, there is no government or pharmaceutical funding for research and/or a cure. This issue has been left to the heart broken families who know that they will lose their child to this terrible disorder. Recently, the families were able to fundraise enough for the NBIA organization to obtain BPAN mouse models. We are still in the beginning phases of research, and in need of funding to further the knowledge of this disorder. Our goal is to come up with medications that can stop the progression, or what we are all hoping for, a cure.

Madison is such a strong little girl, who has been through so much in her 9 years of life. She loves music, dancing, cuddles, and giving the world's best hugs. She recently underwent brain surgery, and a follow up MRI confirmed that there is iron accumulating in her brain. She is nonverbal but has a few words and communicates using an IPad talking device. She does 30+ hours a week of therapy and has worked so hard for

Web site: www.NBIAdisorders.org TAX ID 33-0712327

## 2<sup>nd</sup> Annual Madi's Miracle

Anthony's Restaurant and Pub 3151 Voyager Lane, Joliet IL

## Saturday, September 23, 2017

2pm-7pm Adult Tickets: \$25/person - kids free \*Food \*Cash bar

\*Live Bands \*Silent Auction \*Raffle baskets Raffles drawn at 6pm (must be present) Silent Auction does not have to be present









the progress she's made, all of which will be lost if we don't find a cure. This disorder has a second phase of rapid onset neurological deterioration marked by Parkinsonism and Dementia in teen to early adulthood years.

Your support is invaluable to us. Our daughter and other children like her are depending on the generosity of others to save their lives. Please help us find Madi's Miracle.

Madi's Family

Madi's page: <a href="https://m.facebook.com/MadisMiracle4BPAN/">https://m.facebook.com/MadisMiracle4BPAN/</a>

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