

Letter from the Tifone Family

Dear Friends,

Our son, Adam, was diagnosed with **Neurodegeneration with Brain Iron Accumulation (NBIA)** in March 2007. NBIA is a rare, genetic, progressive neurological disorder that affects approximately two people per million. The common feature among all individuals with NBIA is iron accumulation in the brain, along with a progressive movement disorder, which can result in clumsiness, difficulty controlling the body and speech problems. Some individuals eventually lose the ability to walk, talk, and become totally dependent on others for all their needs.

We are working hard to raise funds to find treatments and ultimately a cure for NBIA. This December, we hope to fund as many of the 2015 Research grant applications that our Scientific & Medical Advisory Board believe will advance our search for a cure. Because of our past efforts, we have increased the number of researchers interested in working on NBIA - now we have to help them make that research possible. The average grant request is \$45,000.

The National Institute for Health (NIH) funding is at an all-time low. It is very difficult for rare diseases like NBIA to get those federal funds. If we are to keep the hope for a cure alive in this climate, it is important that the NBIA Disorders Association take a lead role in helping fund research. We are doing our best to keep and attract new researchers to study NBIA disorders.

You can make a difference by supporting our event. Your support gives Adam and all others with NBIA the gift of HOPE.

Sincerely,
Rick and Diane Tifone

How Do I Get Started?

- Fill out and sign the NBIA Marathon Commitment Form. Mail the completed form with your donation to the Marathon Organizers.
- If you will be golfing, you will receive a complete Marathon packet via e-mail answering a number of questions and providing helpful suggestions. You will also receive a sample email to solicit pledges and instructions on how to create a FirstGiving Page for online donating.
- Begin contacting Sponsors/Pledges!
- Our goal is to raise \$35,000.

For more information:

Contact Rick or Diane Tifone at 412-492-7495; email rtifone@verizon.net or dtifone@verizon.net or visit:

www.nbiagolfmarathon.com.

About NBIA Disorders Association

NBIA Disorders Association has been working since 1996 to raise money for research, public awareness campaigns, and to provide support to affected families. 100% of the net proceeds from family fundraisers go directly to the research fund and all employees are unpaid volunteers. For every \$100,000, the association can sponsor a year of medical research which can ultimately lead to a larger grant by NIH and the discovery or a cure and future prevention.

www.nbiadisorders.org

NBIA Marathon Commitment

By signing the form below, I understand I am making a commitment to participate in this fund raiser for NBIA. As a golfer participant, I will do my best to reach my personal goal of \$1,250.

- Yes! I am golfing and sponsoring myself at \$ _____
(\$125 minimum donation and target pledges of \$1,250)
- Yes! I will Caddy for _____.
(\$75 minimum donation and target pledges of \$500)
- Yes, I will be a Virtual Golfer (\$100 minimum donation and target pledges of \$1,000)
- Yes, I will be an Event Sponsor for \$2,500 donation.
- Yes, I will be an Eagle Sponsor for \$1,000 donation.
- Yes, I will be a Birdie Sponsor for \$500 donation.
- Yes, I will be a Par Sponsor for \$250 donation.
- I Can't play but would like to contribute \$ _____

Name

Address

Phone

Email

Signature

**Please Mail Completed
Commitment Form and \$125
donation by August 30, 2015
to:**

**Rick Tifone
4791 Au Sable Dr.
Gibsonia, PA 15044**

Questions: (412) 492-7495

About the Marathon

Do I have to play 100 holes? No. Play as many as you want. After lunch, we will have a keg of beer so if you get tired of golfing you can enjoy the fall afternoon and watch us diehards go buzzing around the course. If you plan on playing only a round or two, please focus on flat pledges or donations instead of per hole pledges.

Do I have to be a good golfer? No! However, you do need to be able to swing the club. A little stamina will go further in this event than pure talent.

How is the Marathon run? Registration begins at 8:00 am with a continental breakfast. (Lunch, Dinner and On-Course drinks all day are included). You'll be paired with one other person (of your choice). Each golfer has his or her own private cart. 8:30 am shotgun start and off you go! Special rules are in effect to speed play along such as playing three balls on all par 3s.

How am I going to raise \$1,250 in pledges? You can do it! It's just 10 people at \$1.25 per hole. At our last event we averaged more than \$1,000 per golfer. We will provide you with an email template and PDF pledge form that you can send to your contacts.

Do I have to collect the money? You collect the money for flat pledges/donations. We collect the money for per hole pledges. We will contact your donors via e-mail after the marathon and let them know how well you did and say thanks for helping Adam and all the people with NBIA.

If I don't raise \$1,250 can I still play? Yes! The goal is 25 golfers with at least \$1,250 in sponsorships. We ask that you do your very best in getting as many sponsors as possible.

Can I register as a caddy? Yes, if you have a golfer that you would enjoy spending the day buzzing around the course with you can register as a caddy. A caddy must sponsor themselves for a minimum of \$75 with a goal of \$500 in pledges.



I can't play but would still like to contribute. How can I help?

Fill in the Commitment form and mail in your pledge/contribution as a form of support.

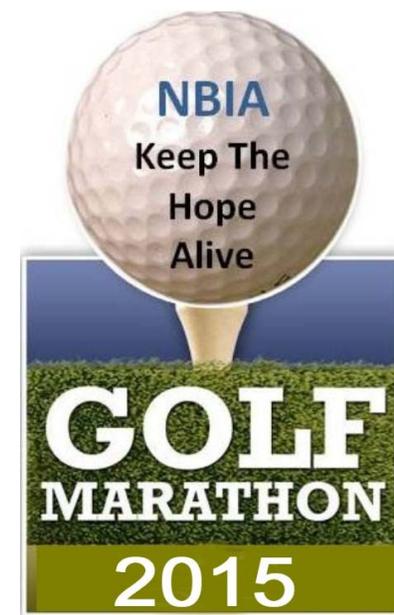
**Lake Arthur Golf Course
Butler, PA 16001
September 25, 2015**



Please Mail Completed Commitment Form and \$125 donation by August 30, 2015 to:

**Rick Tifone
4791 Au Sable Dr.
Gibsonia, PA 15044**

**Lake Arthur Golf Course
Butler, PA 16001
September 25, 2015**



Supporting

