



**Good Morning. I want to thank Gerry for inviting me to speak to you today - August, 2005**

I wish that I could be there in person with all of you.

My name is Mark Michalisin, and I first met the Barbiero family 7 years ago when they moved into our neighborhood in Niskayuna, NY. I was instantly drawn to Sabrina's warm smile and Alyssa's repeated attempts to flirt. Back then, I had never heard of NBIA, but at that point the Barbieros became part of our lives. Over the years our two families began doing more and more things together – going to a Barney concert, going to the circus, bowling, apple picking, and family cookouts. It slowly became apparent that something was not quite right with both Sabrina and Alyssa. Finally there were answers. Great news, we finally found out what was wrong. The bad news, it was an unknown condition with no cure thus far. The only way to get to the bottom of this was to help raise money to fund the needed research and find a cure. Today this is the biggest challenge we face. That is why I am speaking to you today.

We decided to do something that we know a lot about – eating and having fun. Family, friends and neighbors of the Barbieros joined together in January of 2003 to begin planning a community-wide Family Fun Day, which was to be held that October. We began passing fliers around our neighborhoods, advertising in the schools, reaching out to local businesses, as well as national businesses, for donations and sponsorships, and the response was overwhelming. The day consisted of a family fun walk, clowns, face painting, hair braiding, a local DJ, a BBQ, and raffle drawings. I can tell you that a lot of the money came from the raffle drawings, which included such prizes as leather jackets, gift certificates to local establishments, TVs, DVDs, and airline tickets, all of which were donated. It was truly a community event, and we raised over \$75,000, which included a \$50,000 research grant from a local company. Both Sabrina and Alyssa had a blast that day. Much of their family and friends were there to share this special day with them. Also sharing this special day was Cheryl Lamos and her family from East Greenbush, NY. Cheryl's children, Bruce, Becky, and Barbara, all of whom share this disorder, had a great time as well.

Our next fundraising endeavor was inspired by the passing of Sabrina in March of 2004. I wanted to dedicate something to her memory, so I decided to compete in a triathlon to raise money for NBIA research. I contacted my family, friends, and co-workers, and once again, everyone came through. The event was held in August of 2004 in Vermont, and Gerry, Bela, and Alyssa were there with me, along with family and some special friends. This day was just as important to Alyssa as it was for me, so I pushed her across the finish line in her wheelchair. The smile on her face was priceless. I raised almost \$10,000. Again this August, I will compete in the same triathlon, but this time the girls' Uncle Anthony and his friends will compete too.

Sadly, Alyssa will not be there with us, but along with Sabrina, her spirit will help us through. Who knows, maybe we will see another upside down rainbow symbolizing the girls' approval to us.

The most recent Niskayuna-wide fundraiser was held just a few short weeks ago to raise money for a handicapped swing at the girls' elementary school. Again, through the community, family and friends, over \$7,500 was raised.

Unfortunately, I think we have tapped out our local monetary resources over the past couple of years.

Each quarter, a newsletter is sent out updating each of us on the progress of NBIA research, updates on gatherings, events and the tragic loss of yet another life. I receive these newsletters and one common theme comes across – Fundraising. In order to further research, we need to continue to raise money. Yet, it appears that the same group of families is spearheading the events.

If one person can raise over \$10,000, what do you think could happen if we all committed ourselves to this cause? There are generous, warm-hearted people out there who are willing to contribute, but they are not aware of our cause. Just imagine what can be accomplished if we pull together and commit to doing it? It's easy, all you have to do is ask.

Awareness is the key to success. All it takes is a little time and effort to make the general public aware of our cause. Without funds, we do not stand a chance of finding a cure for this disorder. Every little bit helps. Set up a bake sale at school, organize a fun walk or bowl-a-thon, ask local businesses to help. A little effort will return a bountiful of rewards. This disorder has affected each of us in this room – either through a family member or a close friend. My life is that much more rewarding to have been a part of Sabrina and Alyssa Barbierio's lives, and I am committed to doing everything I can to raise awareness and funds to find a cure for NBIA.

The goal of this discussion is to focus on the importance of fundraising. Without it, research can not continue. I challenge the members here today to come up with a goal for 2005 and commit to achieving it. Each and every one of us needs to take the responsibility to do their part. Together, we can achieve not only our goals but continue the research to find a cure for NBIA. Thank you for your time and commitment to a worthwhile cause.

